DOCUMENT RESUME

ED 476 375 EC 309 575

AUTHOR Rader, Rick, Ed.
TITLE Exceptional Parent, 2002.
ISSN ISSN-0046-9157
PUB DATE 2002-00-00
NOTE 1422p.
AVAILABLE FROM Psy-Ed Corp, Exceptional Parent Magazine, 65 East Route 4, River Edge, NJ 07761 (Annual subscription: $39.95). Tel: 877-372-7368 (Toll Free); Web site: http://eparent.com.
PUB TYPE Collected Works - Serials (022) -- Guides - General (050)
JOURNAL CIT Exceptional Parent; v32 n1-12 Jan-Dec 2002
EDRS PRICE EDRS Price MF11 Plus Postage. PC Not Available from EDRS
DESCRIPTORS *Child Rearing; *Disabilities; Early Childhood Education; Educational Needs; Elementary Secondary Education; Infants; Medical Research; Organizations (Groups); Resources; Stress Management; Technology; Toys; Transitional Programs

ABSTRACT

Twelve monthly issues of this magazine for parents and others concerned with children with disabilities are contained in this document. Individual issues typically include a number of articles based on the issue's theme, a special report, research reflections, and regular columns covering news items, practical answers to child rearing problems, book reviews, a legislative update, new products, and a children's page. A continuing series addresses the oral health of people with disabilities. Individual issues address the following themes: (1) organizational and agency resources; (2) early childhood; (3) life planning; (4) medical research; (5) transitioning; (6) technology; (7) teenagers and young adults; (8) infant health and development; (9) education; (10) toys; (11) stress management; and (12) family and community. Other topics highlighted in various issues include autism and the measles/mumps/rubella vaccine, making summer plans, mobility, the treatment of childhood movement disorders, research on traumatic brain injury, adaptive track and field, military special programs, empowering parents, a listing of schools and camps, and assistance dogs. (DB)

ENTIRE DOCUMENT:
POOR PRINT QUALITY

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 476 375

EXCEPTIONAL PARENT

January 2002-December 2002
Volume 32/Number 1-12

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

PERMISSION TO REPRODUCE AND
DISSEMINATE THIS MATERIAL IN
MICROFICHE ONLY HAS BEEN GRANTED BY

J.H. Valenzano

TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)

2B

EC 309575

BEST COPY AVAILABLE

Information and Support for the Special Needs Community
PARENTS ◦ FAMILIES ◦ PHYSICIANS ◦ PROFESSIONALS

EP
Exceptional Parent

JANUARY 2002
$19.95

2002 RESOURCE GUIDE

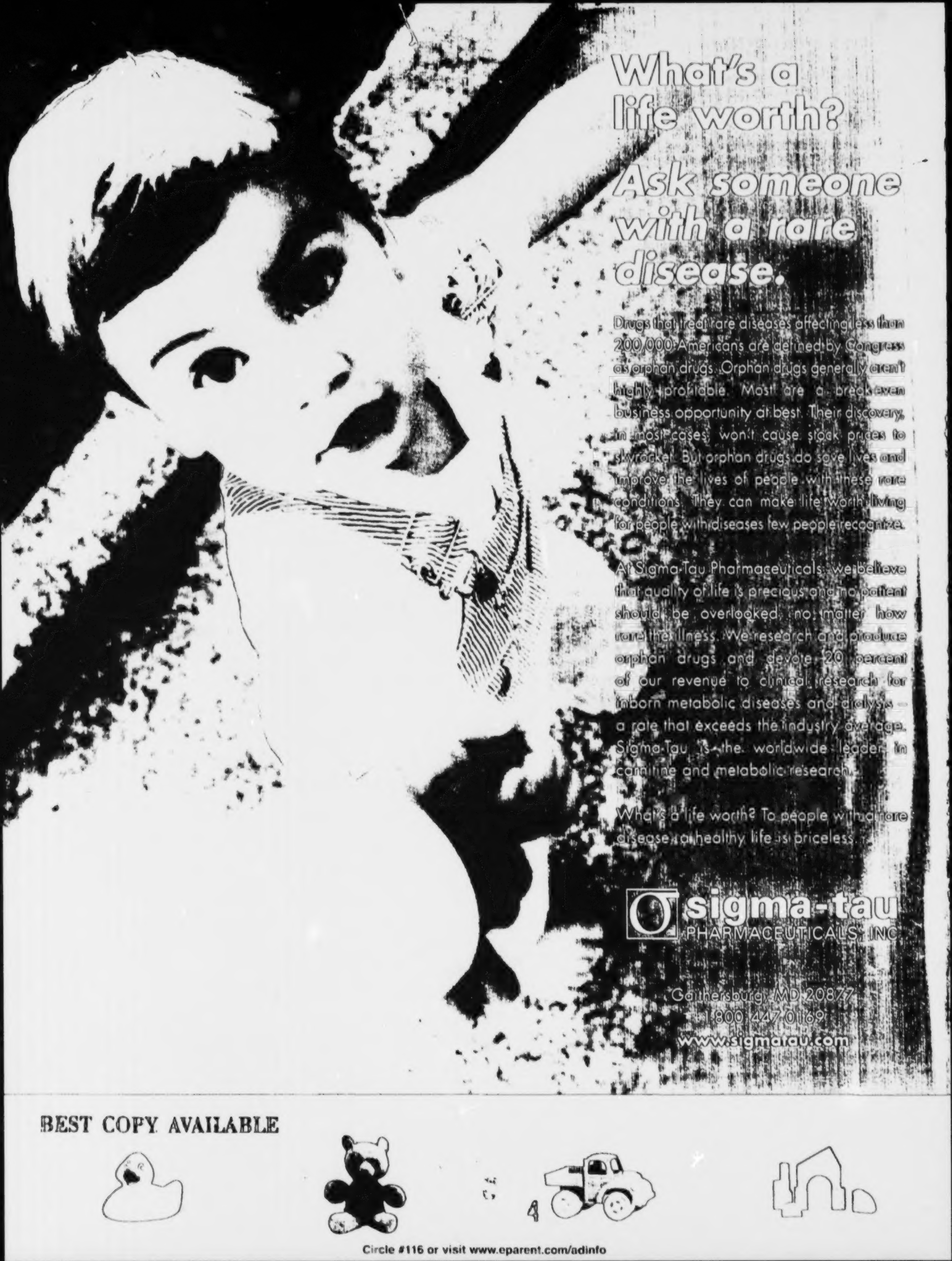
KNOWLEDGE IS POWER

****************ALL FOR ADC 220
GENERAL OC
COUNCIL FOR EXCEPTIONAL CHILDREN
1110 GLEBE RD., STE. 300
ARLINGTON VA 2[redacted]
R=29566
S510 P1

22202

BEST COPY AVAILABLE

www.eparent.com



What's a life worth?

Ask someone with a rare disease.

Drugs that treat rare diseases affecting less than 200,000 Americans are defined by Congress as orphan drugs. Orphan drugs generally aren't highly profitable. Most are a break-even business opportunity at best. Their discovery, in most cases, won't cause stock prices to skyrocket. But orphan drugs do save lives and improve the lives of people with these rare conditions. They can make life worth living for people with diseases few people recognize.

At Sigma-Tau Pharmaceuticals, we believe that quality of life is precious and no patient should be overlooked, no matter how rare the illness. We research and produce orphan drugs and devote 20 percent of our revenue to clinical research for inborn metabolic diseases and dialysis – a rate that exceeds the industry average. Sigma-Tau is the worldwide leader in carnitine and metabolic research.

What's a life worth? To people with a rare disease, a healthy life is priceless.

sigma-tau
PHARMACEUTICALS, INC.

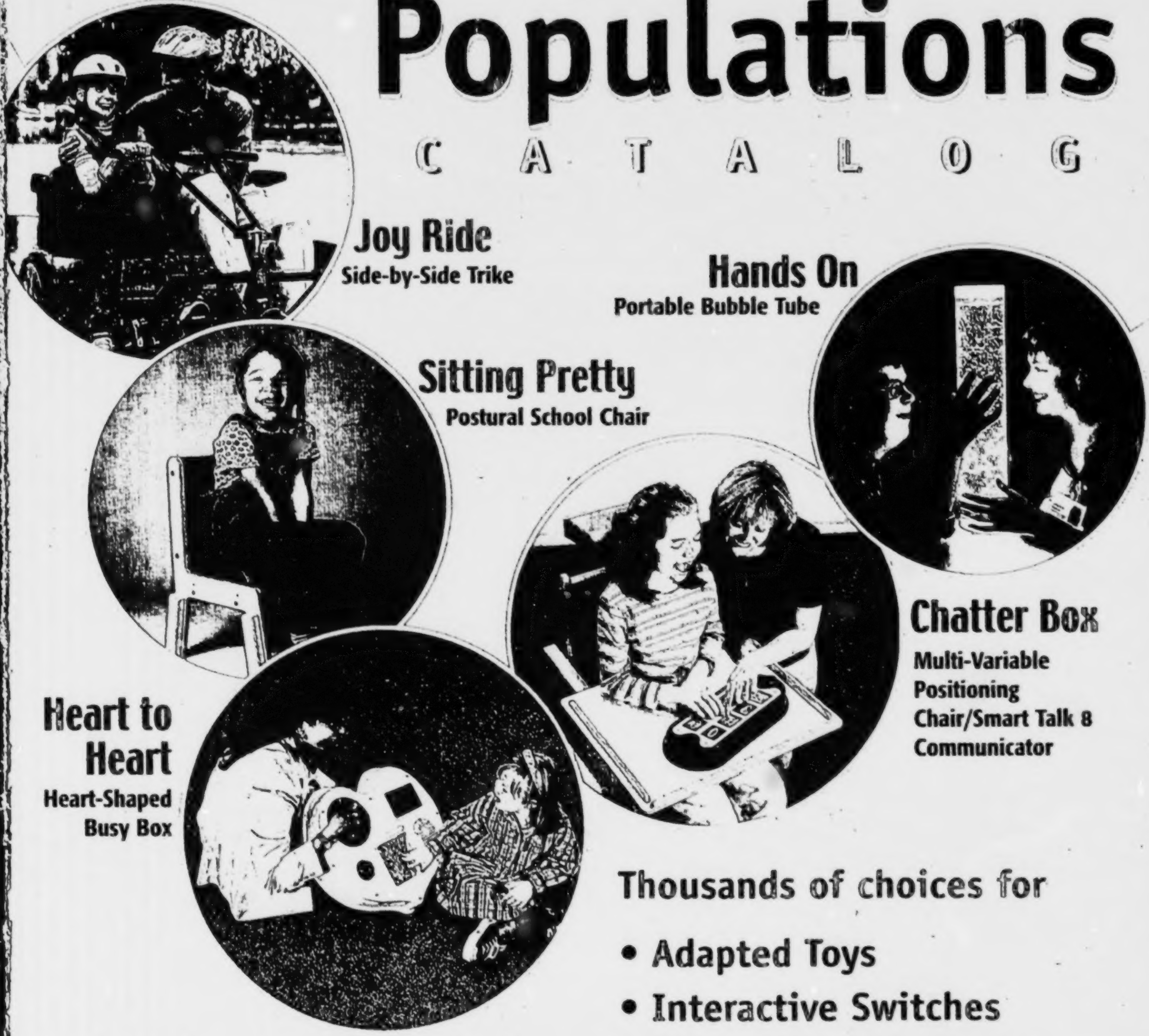
Gaithersburg, MD 20877
1-800-447-0169
www.sigmatau.com

BEST COPY AVAILABLE

Circle #116 or visit www.eparent.com/adinfo

FLAGHOUSE® Special Populations

CATALOG



Joy Ride
Side-by-Side Trike

Hands On
Portable Bubble Tube

Sitting Pretty
Postural School Chair

Chatter Box
Multi-Variable
Positioning
Chair/Smart Talk 8
Communicator

Heart to Heart
Heart-Shaped
Busy Box

Thousands of choices for

- Adapted Toys
- Interactive Switches
- Communication Devices
- Balls, Games, Ride Ons
- SNOEZELEN®

And much more...

For a catalog
Call 800.793.7900
Fax 800.793.7922
e-Mail sales@flaghouse.com

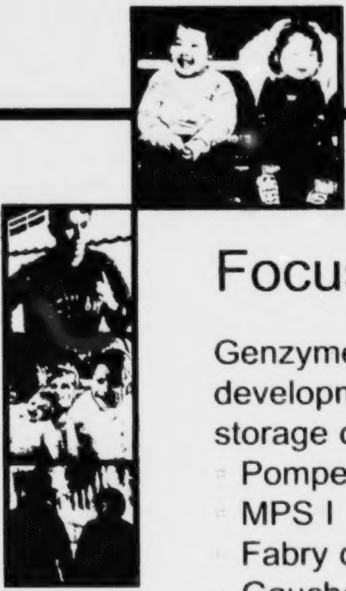
FlagHouse
601 FlagHouse Drive, Dept. XCATX
Hasbrouck Heights, NJ 07604-3116

Because all children have the ability to enjoy life!

Circle #57 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

a rare kind of care



Focused Research

Genzyme is committed to the research and development of therapies for lysosomal storage disorders including:

- Pompe disease
- MPS I
- Fabry disease
- Gaucher disease
- Niemann-Pick disease type B

Unparalleled Support

Genzyme offers comprehensive resources for patients and those who care for them.

- Insurance support
- Disease education and training
- Disease registries
- Medical assistance and advice
- Access to free diagnostic screening
- Genetic Leadership Collaborative

IT'S A RARE KIND OF CARE.
AND IT'S ONLY FROM GENZYME.

genzyme

WWW.GENZYME.COM
ONE KENDALL SQUARE / CAMBRIDGE, MA 02139
800-745-4447 / 617-768-9000

©2001 Genzyme Corporation. All rights reserved.

Circle #63 or visit www.eparent.com/adinfo

There's no place like home.™

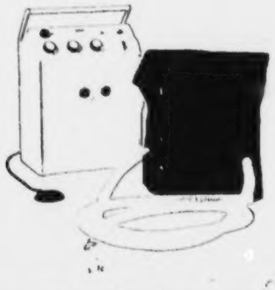
Living at home is the ultimate goal for many with chronic illness or disability. Frequent respiratory complications may make this goal seem impossible. The Vest™ Airway Clearance System has made the difference for Zack. He's now enjoying childhood at home with his family. And as they say, "There's no place like home."

Zack, The Vest™ system user since 1997

More than 2,400 physicians have prescribed The Vest™ system for 20,000 patients with respiratory complications associated with more than 280 diseases and conditions.

The Vest™ system is:
- Widely accepted
- Evidence-based
- Easy to use
  - All lobes of the lungs treated simultaneously
  - Positioning not required
  - Breathing techniques not required
  - Aerosolized treatments can be delivered simultaneously
- Suitable for home and hospital use
- Patient training provided

For more information about The Vest™ Airway Clearance System, call us at 1-866-411-VEST or visit www.thevest.com.



The Vest™
Airway Clearance System

So everyone can breathe a little easier®

The Vest™ and "So everyone can breathe a little easier®" are trademarks or registered trademarks of Advanced Respiratory. © 2001 Advanced Respiratory 501017 AB 11/01

Circle #18 or visit www.eparent.com/adinfo

QUESTCOR

Questcor Pharmaceuticals is proud to keep available

H.P. Acthar® Gel

(repository corticotropin injection)
in 16% gelatin

Visit www.acthar.com for more information

Questcor Pharmaceuticals, Inc.
3260 Whipple Rd.
Union City, CA 94587

By prescription only

PM 104.00

Circle #109 or visit www.eparent.com/adinfo

Informed Parents

Where Parents Keep Up To Date On Products For Their Children's Special Needs

The Kangoo

Rehab Stroller,
Bike Trailer,
Snow Ski Buggy,
and coming soon,
Car Seat Option

Introducing

The Gator

The Buffalo

The Tiger

Introducing
The Panda Futura

The Flamingo

Introducing
The Wombat

BEST COPY AVAILABLE

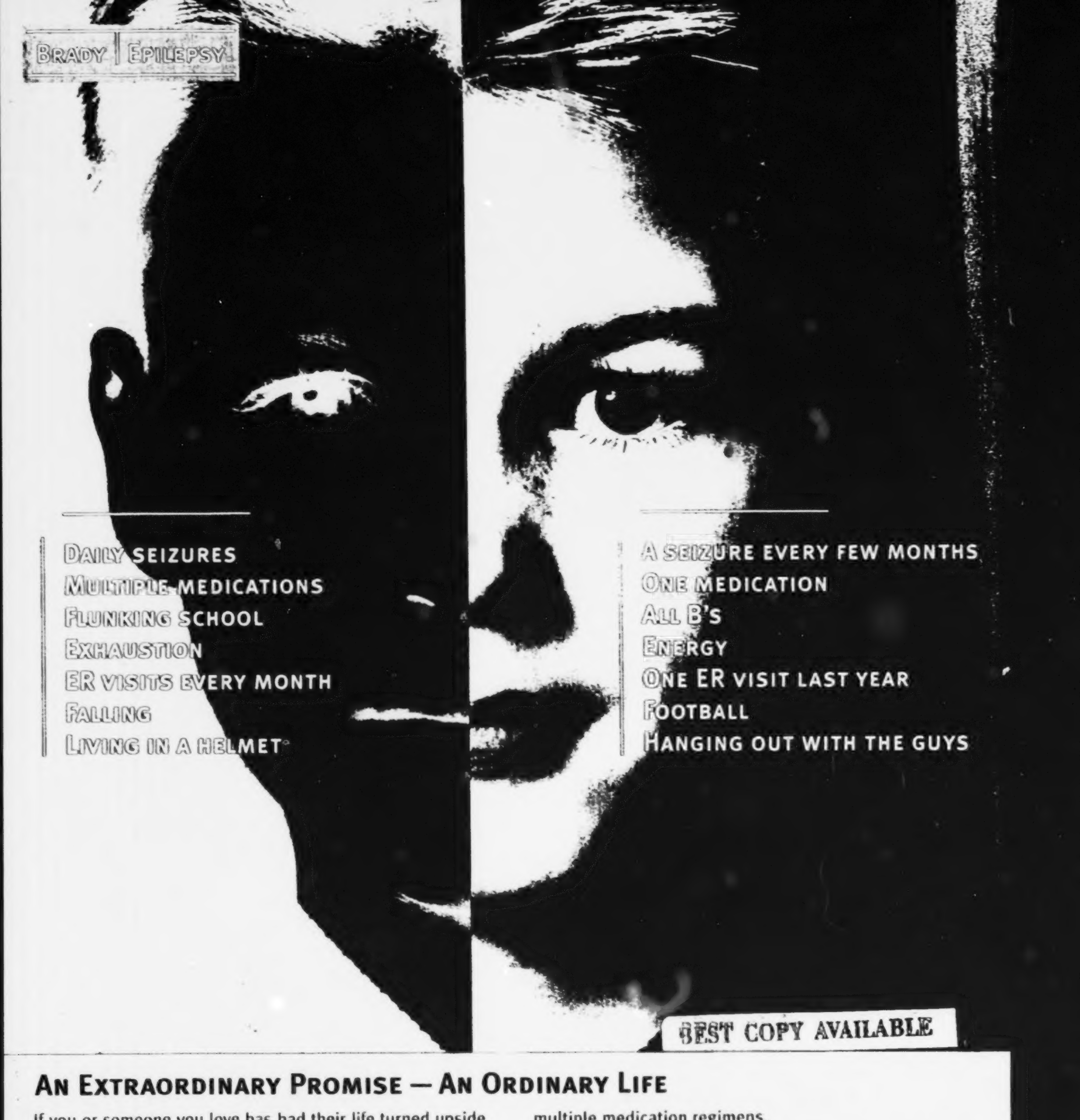
Information
1-800-336-7684
snugseat.com

LOOK FOR US EVERY MONTH IN EXCEPTIONAL PARENT!

VISA
MasterCard

SnugSeat®

Circle #118 or visit www.eparent.com/adinfo


BRADY | EPILEPSY
DAILY SEIZURES
MULTIPLE MEDICATIONS
FLUNKING SCHOOL
EXHAUSTION
ER VISITS EVERY MONTH
FALLING
LIVING IN A HELMET
A SEIZURE EVERY FEW MONTHS
ONE MEDICATION
ALL B'S
ENERGY
ONE ER VISIT LAST YEAR
FOOTBALL
HANGING OUT WITH THE GUYS

BEST COPY AVAILABLE

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

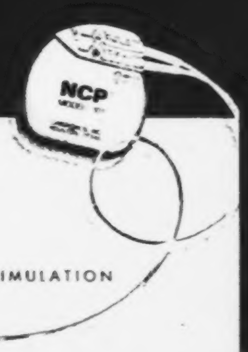
So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

BEST COPY AVAILABLE



VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS

VAGUS NERVE STIMULATION

Cyberonics

Circle #51 or visit www.eparent.com/adinfo

The EP Family wishes all our readers a wonderful 2002!

Front row (l.-r.) Lauren Agoratus with daughter Stephanie; J.M. Della Valle; Bridget Lyne; Robyn Sager (in front of Bridget); Joe Valenzano with grandchildren Alexis and Christian; Rob D'Angelo; Dolores Kinley; Ann Weber; Dennis Dusevic; Back Row (l-r.) Rick Rader; Pete Redman; Mike Longobardi; Nancy Derbyshire; Ron Richards; Vanessa Ira; Matt Valenzano; Jared Adams; Esther Schleifer; Fern Potvin; Doris DeFina; Kendra Kelly (behind Doris); Mike Valenzano; Dennis Wilkes; Susan Jenkins.

contents

JANUARY 2002 ◦ VOLUME 32, ISSUE 1

RESOURCE GUIDE 2002

KNOWLEDGE IS POWER: It is ironic that the brain and its frailties are responsible for the majority of the genetic or acquired disabilities that EP addresses every month. However, the human brain is also a vast resource storehouse and is capable of forming neural networks which serve to transmit sensory information. The 2002 EP Resource Guide may be thought of as a printed repository of thousands of resources that can help users grow in knowledge to find new networks and pathways in advocating and caring for someone with any disability. That knowledge gives power to those who are trying to make life with a disability more livable.

This year, to make the Resource Guide more user-friendly, we have fashioned descriptions of each directory to anticipate questions which may arise for parents and professionals in their search for particular information. We have highlighted in bold some of the key phrases that may spark a connection. The editors at EP express their special thanks to Betsy Santelli the director of the Parent to Parent projects of the Beach Center on Families and Disability at the University of Kansas for compiling these "frequently asked questions."

And as always, we heartily thank all the organizations and associations for contributing their directories and being a part of this issue. Thanks, too, to EP staffers Kendra Kelly and Dolores Kinley for the cover selection. The EP staff wish everyone a great new year and "More Power to You!"

Does your family member have a **specific disability diagnosis** or **specific symptoms of a disability** for which you would like more information? Do you want to **connect to a group** of people coping with similar challenges who can direct you to **local resources** for that specific disability in your area?
See the **National Resources for Specific Disabilities** followed by **Matching Resources** **22**

Would you like to be matched one-to-one with another parent whose family and disability experiences are similar to your own? Would you like to receive **information and emotional support from other parents** who have "been there"?
See the **Parent to Parent Programs** **54**

Are you looking for information about how to meet the **educational needs** of students with disabilities—from infant to young adult —and their families?
See the **Parent Training and Information Centers** around the country are there to help parents and professionals **58**

Are you looking for services in your area to enable your family member with developmental disabilities **to participate in the community**? Interested in learning more about research and best practices for serving people with disabilities and their families?
See the **Association of University Centers on Disabilities** **66**

ERIC Clearinghouse on Disabilities and Gifted Education
Arlington, VA 22201-5704

contents

Do you need **adapted equipment or technology** for a family member with special needs or information about funding to pay for assistive technology devices?
See the **Alliance for Technology Access Centers** directory **69**
See the **State Assistive Technology Programs** directory **71**

Would you like to know how your family member with special needs can **participate in sports or recreational activities?**
See the directory of **Adaptive Recreation Organizations** **80**

Are you looking for a hospital in your area that **specializes in treating children** and specialty disorders?
See the NACHRI's **Children's Hospitals** directory of member hospitals including some which do not bill for services **82**

Need **health-related services** for a child with special health care needs, parent support or information?
See the state program's listing in the **Title V** directory **85**

Looking for information, technical assistance, or training on **meeting Americans with Disabilities Act standards** in a business, public area, or school?
Try your regional center in the **ADA Projects** directory **87**

Do you have an infant or toddler (birth to three) with special needs and need information and services—from **preschool education to therapies**—for that child?
The **Early Intervention** directory lists your state's program **94**

Information about a variety of disability-related topics—from specific disorders to employment—is available from the Federal government.
See the **Federal and Federally Funded Information Resources** **100**

Need information or services that are related to **many areas of living with a disability** including accessible travel, independent living, caregiving, respite, adoption, and adaptive toys?
Try the **National Information and Advocacy Resources** **102**

Do you need information on a disorder that affects **movement?**
Turn to the **International Guide to Movement Disorder Patient Advocacy Groups and Foundations** from WE MOVE **108**

Do you have concerns about the whether your child's **rights to special education services** are being properly respected? Do you need referral to **local resources?**
See the **State Directors of Special Education** for your state's agency which oversees special education services **116**

Are you looking for information and local resources available to meet the **healthcare** needs of children with disabilities and chronic illness in your area? Do you want to work with others to **influence healthcare policies?**
See the **Family Voices State Contact** list for your state's coordinator **123**

Do you need help advocating for the **legal rights** of your family memberwith a disability?
Look at the **State Protection and Advocacy Agencies for Persons with Developmental Disabilities, Mental Illness and the Client Assistance Program (P&A)** for your state's programs **127**

Need information and support for caring for a family member who has **challenging behaviors, emotional disabilities or mental health issues?**
See the directory of organizations that form the **Federation of Families for Children's Mental Health** **152**

Do you have a young adult with a disability who is entering the world of **employment** or is already employed? Would you like to know more about **training and rehabilitation services** that are available in your state?
See the directory of **Vocational Rehabilitation Programs** **157**

What **issues** did EP cover in 2001?
See the **EP Editorial Index 2001** **159**

Are you looking for **family support and disability-related resources** in Canada?
See the **Canadian Resources** **167**

Editor's Desk **14**
EP Library contains nearly one thousand books and videos on disability **130**
Directory of Products and Services **183**
Product Showcase **200**
Marketplace **202**
Editorial Calendar **204**

Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy-Ed Corp., dba *Exceptional Parent Magazine*, 65 E. Route 4 River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy-Ed Corp. *Exceptional Parent*® is a registered trademark of the Psy-Ed Corp. **Postmaster:** Please send address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43305-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43305-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service. *Exceptional Parent.* Back issues incur a charge of $6.50 each and depend upon availability, call (800) 372-7368. Agreement # 1420542

Exceptional Parent neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

EP
Exceptional Parent

BEST COPY AVAILABLE

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at
DISCOUNT PRICES!

As a service to our customers, we offer
FREE SAMPLES
of disposable youth briefs and pull ups.

Save up to 50%
Call **1 800 777 1111** 24Hrs
WOODBURY PRODUCTS, INC.
Order online at: **www.woodburyproducts.com**

Circle #140 or visit www.eparent.com/adinfo

Discover
New England Village, Inc.
"A community rich with opportunity, sharing and growth"

Established as a non-profit corporation in 1972, New England Village is a warm, caring stable and secure environment where young adults with mental retardation can lead a high quality lifestyle with opportunities for growth and friendship.

Our campus, set on 80 beautifully wooded acres just 25 miles south of Boston, offers attractive contemporary style homes and townhouse apartments. Learn about our full range of residential options, extensive vocational and education programs, and wide spectrum of recreation and social opportunities. We invite you to meet our dedicated and caring staff and speak to other families about our village.

Call (781) 293-5461, or write Judy Andracchio, Admissions Coordinator, to arrange your personal visit or request our brochure. We invite private and state-sponsored referrals.

New England Village, Inc.
664E School Street • Pembroke, MA 02359
781-293-5461 • website: **newenglandvillage.org**
email: **info@newenglandvillage.org**

EXCEPTIONAL PARENT MAGAZINE
Information and Support for the Special Needs Community

EDITOR-IN-CHIEF	Rick Rader, MD
MANAGING EDITOR & VP OF MEDICAL EDUCATION	Fern R. Potvin
EDITORIAL ASSISTANT	Nancy M. Derbyshire
INFORMATION SYSTEMS COORDINATOR	Dennis Dusevic
RESEARCH ASSISTANT	Susan Jenkins
GRAPHIC CONSULTANT	Dennis Wilkes
PRESIDENT, CEO, & PUBLISHER	Joseph M. Valenzano, Jr.
EXECUTIVE VP/GENERAL MANAGER & ASSOCIATE PUBLISHER	Robert S. D'Angelo
VP BUSINESS DEVELOPMENT & INTERNET PROJECTS	Vanessa B. Ira
VP ORGANIZATION RELATIONS & CONSULTING EDITOR	Bridget M. Lyne
CHIEF FINANCIAL OFFICER	Dolores A. Kinley
AD TRAFFIC MANAGER	Kendra Kelly
SALES COORDINATOR	Doris DeFina
RECEPTIONIST/PUBLIC RELATIONS COORDINATOR	Robyn Sager
ART DIRECTION, DESIGN	Publishers Design Group, Inc., ✉ annpdg@aol.com
PRODUCTION MANAGER/ TRADE SHOW & CONFERENCE MANAGER	Michael Longobardi
EP LIBRARY	Ron Richards (800) 535-1910 ✉ eplibrary@aol.com
WEBMASTER	Ted Doran ✉ webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Jared F. Adams
EASTERN REGION:
(CT, ME, NH, NJ, NY, RI, VT)
✉ jadams@eparent.com
(201) 489-4111,
ext. 211
FAX: (201) 489-0074

Barbara Nastro
SOUTHEAST REGION:
(AL, AR, DC, DE, GA, FL, MD, MS, NC, PA, SC, VA, WV)
SCHOOLS, CAMPS, RESIDENCES & CLASSIFIED
✉ nastro@blast.net
(908) 534-6366
FAX: (908) 534-6941

Annabelle and Gabe Jacobson
MIDWEST REGION:
(IA, IL, IN, KS, KY, MI, MN, MO, NE, ND, OH, OK, SD, TN, WI)
AUTOMOTIVE
THE LYON GROUP
✉ bellyon@megsinet.net
(847) 256-6850
FAX: (847) 256-6819

Larry Battistello
WESTERN REGION:
(AK, AZ, CA, CO, HI, ID, LA, MT, NM, NV, OR, TX, UT, WA, WY)
Marketing Plus
✉ seeme4ads@aol.com
(760) 320-8797
FAX: (760) 320-9728

Vanessa B. Ira
MASSACHUSETTS & INTERNET AD SALES
✉ vieprnt@concentric.net
(201) 489-4111, ext. 209
FAX: (201) 489-0074

Jeffrey Yamaguchi
CANADA, AUSTRALIA, UNITED KINGDOM, & CUSTOM COMMUNICATIONS
ProMedia Communications, Inc.
✉ ProMedComm@aol.com
(905) 796-7931 ext.23
FAX: (905) 454-9671

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

PUBLISHING & EDITORIAL OFFICE
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

SUBSCRIBER SERVICE:
EXCEPTIONAL PARENT
P.O. Box 2078, Marion, OH 43305-2178.

CUSTOMER SERVICE/NEW ORDERS:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

EXCEPTIONAL PARENT magazine was founded in 1971 by Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 186

INTRODUCING

KetoCal®
4:1 Ratio

A Nutritionally Complete Medical Food for Individuals Over One Year of Age who are on the Ketogenic Diet.

- ✓ **4:1 Ratio (Fat : Carbohydrate + Protein)**
- ✓ **Convenient One Step Preparation with a Non-modular Approach**
- ✓ **Nutrient Dense for Children with Low Energy Requirements**

☎ **1-866-KetoCal**

SHS

North American Offices
Corporate Headquarters
SHS North America
P.O. Box 117
Gaithersburg, MD 20884-0117
(800) 365-7354
www.shsna.com

Canada
SHS North America
1200 McGill College, Suite 1100
Montreal, Quebec H3B 4G7
(888) 475-9624

© 2001 SHSNA. All rights reserved. KetoCal is a registered trademark owned by SHS International Ltd.

11/14/01

Circle #115 or visit www.eparent.com/adinfo

Brain health, repair and regeneration are possible!

Children's Neuro
will transform the
pediatric neuro

CHILDREN'S
NEUROBIOLOGICAL
SOLUTIONS

SCIENTIFIC ADVISORY BOARD

STEVE GOLDMAN M.D., PH.D.
Professor of Neurology & Neuroscience
Cornell University Medical College

HARLEY KORNBLUM, M.D., PH.D.
Assistant Professor of Pediatrics
UCLA School of Medicine

JEFFREY D. MACKLIS, M.D., D.HST
Associate Professor of
Neurology [Neuroscience]
Harvard Medical School

RONALD McKAY, PH.D.
Senior Investigator
National Institute of Neurological
Disorders and Stroke

MARK DAVID NOBLE, PH.D.
Professor of Genetics
University of Rochester
School of Medicine

MAHENDRA S. RAO M.D., PH.D.
Section Chief, Stem Cell Program
National Institutes of Aging
Laboratory of Neuroscience

JEFFREY D. ROTHSTEIN M.D., PH.D.
Professor of Neurology & Neuroscience
Johns Hopkins University

EVAN Y. SNYDER, M.D., PH.D.
Assistant Professor of Neurology
Harvard Medical School

CLIVE SVENDSEN, PH.D.
Professor of Neurology & Anatomy
University of Wisconsin Madison

JAMES THOMSON, V.M.D., PH.D.
Associate Professor
University of Wisconsin Madison

ANGELO L. VESCOVI, PH.D.
Co-Director
Institute for Stem Cell Research
Milan, Italy

BEST COPY AVAILABLE

biological Solutions
approach to
logical research

by fostering partnerships among leading neuroscientists that deliver measurable improvements in the lives of brain injured children, and their families. The outcome of this research and education will provide proven treatments and integrated therapies with easily obtainable information, broadly accessible to those in need, assisting informed decision making.

MISSION STATEMENT: Children's Neurobiological Solutions, Inc. (CNS) is a national, non-profit, 501(c)(3) organization, whose mission is to orchestrate cutting-edge, collaborative research with the goal of expediting the creation of effective treatments and therapies for children with neurodevelopmental abnormalities, birth injuries to the nervous system, and related neurological problems. In addition, CNS strives to provide families and health care providers with user-friendly access to state-of-the-art information and education supporting their decision-making processes.

phone 866 267 5580 **email** info@cnsfoundation.org

Circle #40 or visit www.eparent.com/adinfo

Kelly's Random Acts of Kindness Cart

RICK RADER, MD

Physicians are faced with ever-increasing clinical challenges: the emergence of resistant strains of bacteria, clinical decisions being second-guessed by MCO clerks, evidence-based murkiness, and diminishing societal significance. These professional hazards have somehow escaped from doctors' locker rooms and manifested themselves in a drop-off in the number of applicants to medical schools. While these problems are significant, they pale by comparison to the most challenging dilemma facing physicians today: what to do with all the drug company giveaways we bring back from national medical conferences.

This essay doesn't address the promotional extravaganza of bringing a blockbuster drug to market–it's not that cerebral. Instead, it's about recycling stuff and creating something worthwhile from it. And because it's the editorial that appears in EP's 2002 Resource Guide, it's about resources.

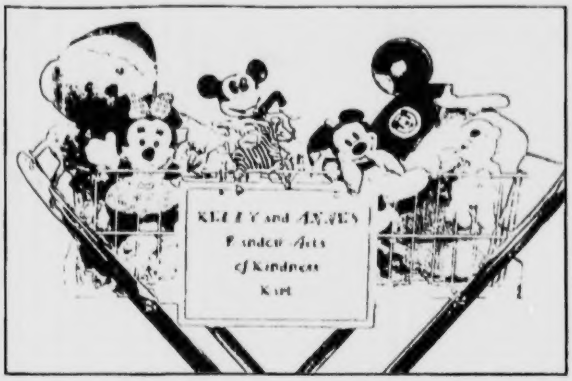
Susan, my assistant, shudders on those Monday mornings when I stroll back into the office overloaded with blue canvas tote bags announcing the next generation of some boutique drug. She shudders because the bags contain not only reports and monographs that translate into weeks of follow-up correspondence, phone calls and new projects, but the mother lode. Out spill pens, note pads, desk toys, small stuffed animals, gadgets, whiz bangs, T-shirts, stethoscope-hugging creatures and every object imaginable that has a surface big enough to display the logo of Intergalactic Drug Co, Ltd. I'm a pack rat, I can't resist this stuff; besides, it's too unwieldy to pack all those steaks and bagels from the focus group dinners and breakfasts. And so I bear gifts.

One afternoon when Susan was taking some college students on a tour of the Habilitation Center, I ventured into her storage closet to find some archival files. It looked like the back room of Toys "R" Us, or as if the elves were working overtime in mid-December. Stuff was overwhelming; it lay on shelves, computer boxes and counter tops, and filled drawers, shopping bags, even mail carts. Two things were certain: I had schlepped my last satchel of nasal congestant boasting finger puppets, and it all had to go. But it couldn't be thrown out; such waste bordered on sacrilege. It had to be moved out but not thrown out, sorta like good ideas before their time.

A few days later Kelly navigates herself into my office. Miss Kelly Bankston is a student at Orange Grove school, a charismatic, delightfully manipulative, never-to-be-forgotten femme fatale. We've become partners in crime. I first "used" Kelly while creating an innovative program several years ago; she was a surrogate patient in a Grand Rounds presentation introducing medical residents and students to the challenges of developmental medicine. It put us both on the cover of EXCEPTIONAL PARENT MAGAZINE and she's been "using" me ever since, mainly as a destination when she goes on excursions throughout the Center. We engage in a wonderful ritual: Kelly comes into my office and asks me if I would call her the next day at home. I nod, and she pantomimes writing; this prompts me to fetch a legal pad and a pen. Then she maneuvers her chair right up to my desk and proceeds to write down her telephone number and name. For a young woman with CP, multiple shunt revisions and enough orthopedic anomalies to give a team of osteoanthropologists a field day, this is no small feat. Several years and several thousand hours of tedious and diligent instruction by her teacher Jenny Chase—rivaled only by the diligent granite chiseling that created Mount Rushmore—resulted in a new skill. Kelly's legible writing is presidential. It's an accomplishment to equal "genius [as] an African who dreams up snow," an observation by Nabokov. For Kelly and Jenny to have dreamed up a strategy to produce a legible scrawl is indeed an amalgam of genius and talent.

Back to Kelly wandering into my office for the ceremonial offering of her phone number. Somehow I get an idea: in addition to stopping in at my office during one of her daily cruises around the Center, maybe Kelly could stop at a few other places. There are lots of destinations at Orange Grove, lots of classrooms, clinics, offices, reception desks, therapy centers, gyms, record rooms and cafeterias, and lots of folks in them, too. I envision Kelly dropping off one of the goodies from Susan's closet at each des-

photos by Dennis Wilkes



tination, for no reason at all.

So we commandeered a mail cart, made some cool signs for the sides of the basket, recruited Anne Patten of the Habilitation Center to assist Kelly, loaded the cart, made a chart and pointed Kelly in the direction of her waiting public. The cart was christened "Kelly and Anne's Random Acts of Kindness Cart," and launched to applause. Kelly didn't need mentoring or tutorials on being nice or engaging or fostering social affiliations any more than a goose needs a GPS. To date, Kelly and Anne have made dozens of sorties throughout Orange Grove and given away enough drug company goodies to put a major dent in the inventory.

Sure, we can translate this newly created "activity " into IEPese: "Kelly will personally deliver small inexpensive donated gifts to staff and students, reap the benefits of social initiation and engagement, and experience the various ways in which people will respond to her." Throw in the "promise " of collecting and recording data and you have the makings of a bonafide educational objective, and we did. But at the end of the day it's just Kelly giving out stuff for no real reason except that she likes to, and that's reason enough for me to keep stocking the closet.

It's a natural equation for success: juxtapose untapped human resources with an overflowing closet clamoring for resource depletion, and you can come up with something– well, something exceptional.

Resources are what EP is all about, and this guide is the best compendium for schools, camps, clinics, therapeutics, products, technology, organizations and people ever assembled. Use it and you just might experience some random acts of kindness yourself.

Rick Rader, MD

Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

THE CENTER FOR CHILDREN • HOSPITAL FOR JOINT DISEASES

Caring for children with
Cerebral Palsy
requires the help of many specialists.

Now you can find them all at
one special place.

The Center for Children is the one place you'll find all the care options you need, with just one concern in mind: your child. By bringing together the resources of the Hospital for Joint Diseases (HJD) and the Rusk Institute of Rehabilitation Medicine (RIRM) of NYU Hospitals Center, we can care for a variety of conditions in one convenient setting. For example, you'll find the widest possible range of treatments for children with cerebral palsy, with in-house specialties including pediatric physiatry, orthopaedics, speech therapy, neurology, neurosurgery, physical and occupational therapy. All in a gentle, kid-friendly environment where there are no white coats, but plenty of color, interaction, toys, games and stimulation. From newborns to 21-year-olds, The Center for Children treats them better. **Call us at 212-598-2330.**

The Center for Children
Hospital for Joint Diseases
301 East 17th Street • New York, NY 10003 • www.jointdiseases.com

For additional comprehensive pediatric services, contact:
NYU Children's Health
866-CHILD-NYU

MOUNT SINAI NYU HEALTH

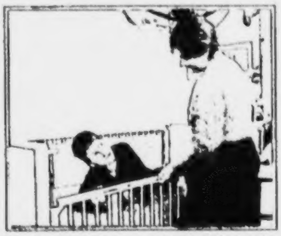
Circle #127 or visit www.eparent.com/adinfo

HARD MANUFACTURING

AGE APPROPRIATE BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas



The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #69 or visit www.eparent.com/adinfo

EP

has the information an "Exceptional Parent" like you Needs

EP
Exceptional Parent

Your paid subscription includes the EXCEPTIONAL PARENT 2003 Annual Resource Guide, which normally sells nationally for $19.95.

This invaluable reference tool is a "must-have" for exceptional parents

Save $5.00
by ordering on-line at:
www.eparent.com

For telephone orders call:
877-372-7368

Circle #299

Subscribe and be part of a network of "Exceptional Parents"

EP

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ________ Exp. Date ________

Name ________

Address ________

City ________ State ________ Zip ________

E-mail ________ Yes, I want more information to help me everyday.

Signature ________ E-mail ________

BJAN2

Subscribe and be part of a network of "Exceptional Parents"

EP

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ________ Exp. Date ________

Name ________

Address ________

City ________ State ________ Zip ________

E-mail ________ Yes, I want more information to help me everyday.

Signature ________ E-mail ________

BJAN2

Make someone a part of a network of "Exceptional Parents"

EP

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ________ Exp. Date ________

Name ________

Address ________

City ________ State ________ Zip ________

E-mail ________ Yes, I want more information to help me everyday.

Signature ________ E-mail ________

XJAN2

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to nework with other who are providing a richer life for themselves and their children.

Exceptional Parent's MISSION

IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

"I feel good about permobil."

"I can see it in her smile. I can feel it when she puts her hand in mine – and even when she zooms off to play. I know we've done the very best we can for her. Her Permobil Koala is more than a wheelchair. Much more."
Uniquely capable. Uniquely your child's. Only from Permobil.

permobil

the art of mobility since 1968

To learn more about our complete line of the best in powered mobility, call **1-800-736-0925**. Or visit our website at **www.permobil.com**

Circle #106 or visit www.eparent.com/adinfo

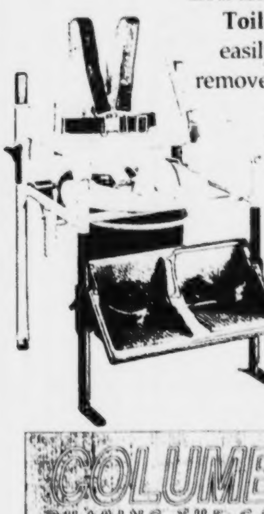
Sally, 40 lbs. and 45" tall, in the #8600 Reclining Bath Chair with #8875 Head Pad

Sharing the Caring

Columbia offers you solutions to the daily challenges of bathing, toileting and transporting your child - *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

☐ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.



#5800 Hi-Back Positioning Commode for junior adults

☐ At bathtime, our popular **Wrap-Around Bath Supports** and **Reclining Chairs** allow your child - and you - to enjoy the bath.

#7200 Wrap-Around Support

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

☐ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.-yet weighs only 11 pounds! Comfort, style and adjustability have made it the No. 1 choice since 1986.

#2000 Car Seat

Why do these products work so well?
Much thought and care go into the design of each Columbia product. We make each item in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, proven in real life. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

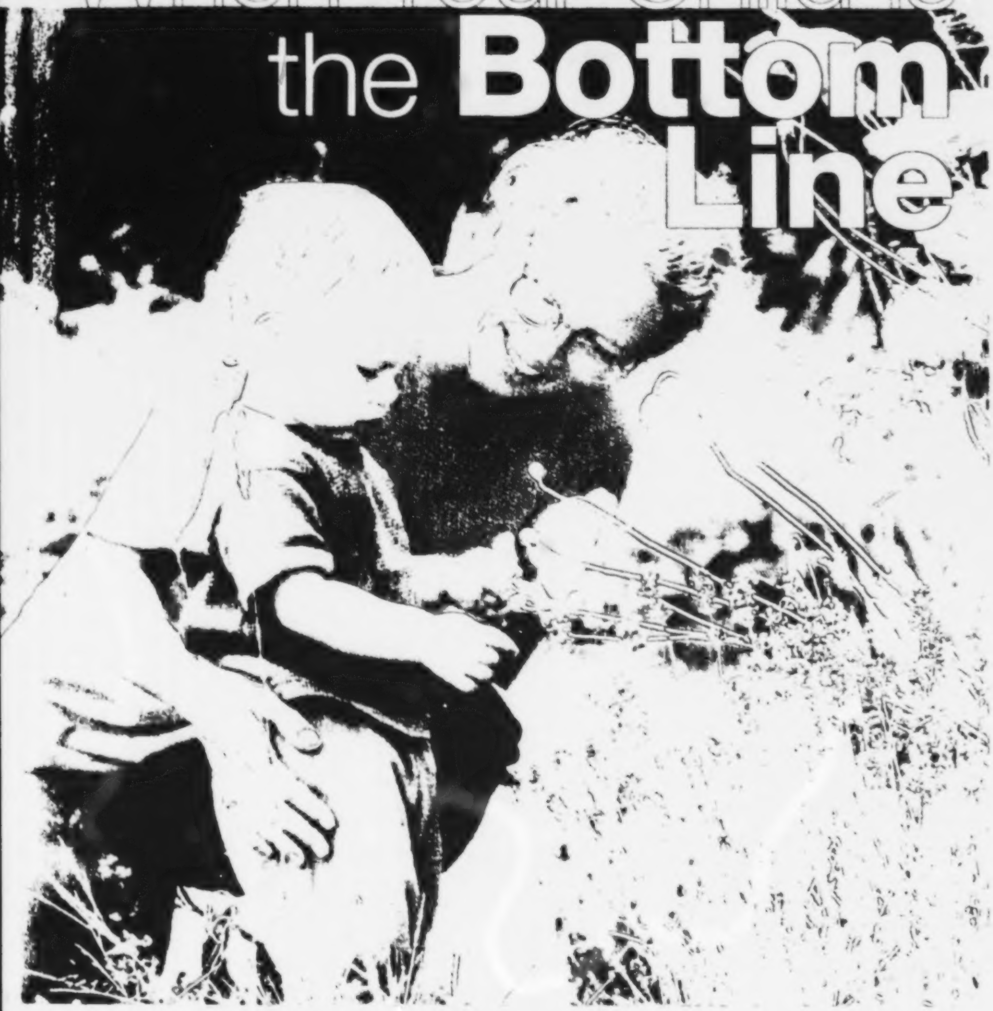
COLUMBIA
SHARING THE CARING

Circle #41 or visit www.eparent.com/adinfo

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG

Columbia Medical Mfg. Corp., Dept D2, P.O. Box 633, Pacific Palisades, CA 90272
Visit our web site at http://www.ColumbiaMedical.com

When Your Child is the Bottom Line



Athena Diagnostics — The most advanced line of Neurological Diagnostic Testing available today:

- ○ *Infant Hearing Loss*
- ○ *Charcot-Marie-Tooth Disease*
- ○ *Neuromuscular Disorders*
- ○ *Developmental Delay*
- ○ *Spinocerebellar Ataxia*
- ○ *Dystonia*

Better Diagnosis for **Better Care**

At Athena Diagnostics, providing the tools your doctor needs to make critical care management decisions is what we are all about.

We've developed the most **comprehensive neurological testing services** and set the standard for the diagnosis of your child.

Making informed decisions has never been easier with a series of advanced diagnostic tests developed in conjunction with leading medical research institutions around the world. With a broader range of information available, you and your doctor will make better decisions regarding your child's care.

Ask your doctor how a diagnostic test from Athena can help you and your child.

For more information, visit our web site at **www.athenadiagnostics.com/parent.**

athena diagnostics®

Four Biotech Park • 377 Plantation Street • Worcester, MA 01605

www.athenadiagnostics.com

Circle #25 or visit www.eparent.com/adinfo

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

This directory includes national groups and organizations that can serve as resources for parents and professionals seeking information and support regarding specific disabilities and conditions. Please note that information on some specific disabilities may also be available from Federal and Federally-Funded Information Resources, Parent to Parent Programs, or certain National Information and Advocacy Resources (see Table of Contents for page numbers). In addition, Matching Resources, at the end of this directory, may also be useful.

CROSS-REFERENCING

Categories have been cross-referenced where appropriate.

Many conditions are known by more than one name. Readers are directed to "See" other relevant category names where resources are also listed. Under CHROMOSOME 4P-, for example, readers are referred to WOLF-HIRSCHHORN SYNDROME.

Some specific disabilities are not covered by a specific national organization. These conditions may be cross-referenced to a broader category that includes organizations that can provide helpful resources. For example, the metabolic condition ARGINASE DEFICIENCY is cross-referenced to UREA CYCLE DISORDERS. In some cases, the reader may be directed to a similar (but not identical) condition, when groups for that condition have indicated the ability and willingness to provide appropriate information and support. For example, 45,X SYNDROME is cross-referenced to TURNER'S SYNDROME and HYPOPIGMENTATION.

In cases where resources are available for both a general category of disability (for example, VISUAL IMPAIRMENT), as well as specific conditions within that general category (for example, ALBINISM; GLAUCOMA; MACULAR DISEASES; RETINITIS PIGMENTOSA, RETINOBLASTOMA; SEPTO-OPTIC DYSPLASIA; and USHER SYNDROME), cross-referencing goes in two directions. Under VISUAL IMPAIRMENTS, for example, readers are informed of the types of visual impairments for which specific resources exist; and under each specific type of visual impairment, readers are referred back to the more general category. The only exception to this type of cross-referencing is the general category MENTAL RETARDATION, which is not used as a cross-referencing term.

In cases where one specific condition usually includes other conditions, but those other conditions do not necessarily include the first condition, cross-referencing goes in one direction only. For example, under LAURENCE-MOON-BARDET-BIEDL SYNDROME (LMBBS), readers are directed to "See also" KIDNEY DISORDERS and RETINITIS PIGMENTOSA, though neither of these conditions refer back to LMBBS. This is because LMBBS typically includes kidney complications and retinitis pigmentosa, but a primary diagnosis of either one of these conditions does not typically include LMBBS.

Cross-referencing assistance came from the organizations listed in this directory, from the National Organization for Rare Disorders (NORD) and their *Resource Guide* (fourth ed., 2000, available for $53.95 including S&H through the EXCEPTIONAL PARENT Library [800] 535-1910; Item Number NO418DI), and from the *Physician's Guide to Rare Diseases* (second ed., 1995, edited by Jess G. Thoene, MD, also available for $45.00 including S&H from the EP Library as Item Number DP1311OD).

USING THIS DIRECTORY

A description of services provided by individual groups follows each listing in this directory. Numbers correspond to items listed in the **Key to Services**, which appears on every other page. When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the symbol, ✉. Web sites are listed with the standard **http://** before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

1-ß-HYDROXYLASE DEFICIENCY

See: *Adrenal Disorders*

17-20-DESMOLASE DEFICIENCY

See: *Adrenal Disorders*

17-ALPHA-HYDROXYLASE DEFICIENCY

See: *Adrenal Disorders*

17-HYDROXYLASE DEFICIENCY

See: *Adrenal Disorders*

21-HYDROXYLASE DEFICIENCY

See: *Adrenal Disorders*

3-ß-HYDROXYSTEROID DEHYDROGENASE DEFICIENCY

See: *Adrenal Disorders*

45, X SYNDROME

See: *Turner's Syndrome; Albinism & Hypopigmentation*

47,XYY; 47,XXY; 47,XXX SYNDROMES

See: *Klinefelter Syndrome*

A-BETA-LIPOPROTEINEMIA

See: *Tay-Sachs Disease*

ABDOMINAL MIGRAINE

See: *Cyclic Vomiting Syndrome*

ACHONDROPLASIA

See: *Growth Disorders*

ACID MALTASE DEFICIENCY

See also: *Glycogen Storage Diseases; Pompe Disease*

(AMDA) Acid Maltase Deficiency Association
PO Box 700248
San Antonio, TX 78270-0248
(210) 494-6144
(210) 490-7161 (fax)
✉tianrama@aol.com
http://www.amda-pompe.org
1,2,6,8,9

ACIDEMIA, ISOVALERIC (IVA)

See: *Acidemia, Organic*

ACIDEMIA, METHYLMALONIC

See: *Acidemia, Organic*

ACIDEMIA, ORGANIC

See also: *Fatty Oxidation Disorders; Maple Syrup Urine Disease; Metabolic Disorders*

Organic Acidemia Association
13210 35th Ave. N.
Plymouth, MN 55441
(763) 559-1797
(763) 694-0017 (fax)
✉oaanews@aol.com
http://www.oaanews.org
1,2,3,6,7,8

ACIDEMIA, PROPIONIC

See: *Acidemia, Organic*

ACOUSTIC NEUROMA

See also: *Balance Disorders & Dizziness; Brain Tumors; Hearing Impairments; Neurofibromatosis; Vestibular Disorders*

Acoustic Neuroma Association
600 Peachtree Pkwy., Ste. 108
Cumming, GA 30041
(770) 205-8211
(770) 205-0239 (fax)
✉anausa@aol.com
http://www.anausa.org
1,2,4,5,6

Acoustic Neuroma Association of Canada
PO Box 369
Edmonton, AB CAN T5J 2J6
(800) 561-2622 (voice/TDD, Canada only)
(780) 928-3384(voice/TDD)
✉anac@compusmart.ab.ca
http://www.anac.ca
1,2,3,5,6; *French materials*

ACQUIRED IMMUNE DEFICIENCY SYNDROME

See: *AIDS*

ACROCEPHALOSYNDACTYLY, TYPE I

See: *Apert Syndrome*

ACROFACIAL DYSOSTOSIS, NAGER TYPE

See: *Nager & Miller Syndromes*

ACROMEGALY

See: *Multiple Endocrine Neoplasia I; Pituitary Disorders/Tumors*

ACTH DEFICIENCY

See: *Adrenal Disorders*

ACYL-COA DEHYDROGENASE DEFICIENCY, MEDIUM-CHAIN

See: *Fatty Oxidation Disorder*

ADDISON DISEASE

See: *Adrenal Disorders*

ADIPOGENITAL-RETINITIS PIGMENTOSA-POLYDACTYLY SYNDROME

See: *Laurence-Moon-Bardet-Biedl Syndrome*

ADRENAL CORTEX MALE PSEUDOHERMAPHRODITISM

See: *Adrenal Disorders*

ADRENAL DISORDERS

National Adrenal Diseases Foundation
505 Northern Blvd.
Great Neck, NY 11021
(516) 487-4992
✉NADFMAIL@aol.com
http://medhelp.org/www/nadf
1,2,3,4,5

ADRENOCORTICOTROPIC HORMONE DEFICIENCY

See: *Adrenal Disorders; Pituitary Disorders/Tumors*

ADRENOGENITAL SYNDROME

See: *Adrenal Disorders*

ADRENOLEUKODYSTROPHY

See: *Leukodystrophy; Tay-Sachs Disease*

AGENESIS OF COMMISSURA MAGNA CEREBRI

See: *Agenesis of the Corpus Callosum*

AGENESIS OF THE CORPUS CALLOSUM

ACC Network
5749 Merrill Hall, Rm. 118
University of Maine
Orono, ME 04469-5749
(207) 581-3119
(207) 581-3120 (fax)
✉um-acc@maine.edu
1,2,3,6,9

AGYRIA

See: *Lissencephaly*

AICARDI SYNDROME

See also: *Agenesis of the Corpus Callosum; Epilepsy; Visual Impairments*

Aicardi Syndrome Awareness and Support Group/Network
29 Delavan Ave.
Toronto, ON CAN M5P 1T2
(416) 481-4095
✉asasn@sympatico.ca
http://www3.sympatico.ca/asasn
2,3,4,7,9

Aicardi Syndrome Newsletter
1510 Polo Fields Ct.
Louisville, KY 40245
(502) 244-9152(telephone/fax)
✉AICNews@aol.com
http://www.Aicardi.com
1,2,3,5,6,7,8

AIDS

CDC National STD and AIDS Hotlines
(800) 227-8922
(800) 342-2437
(800) 344-7432 (Spanish)
(800) 243-7889 (TDD)
✉hivnet@ashastd.org
http://www.ashastd.org
http://www.iwannaknow.org
2,4; *Spanish materials*

National Pediatric & Family HIV Resource Center
30 Bergen St.-ADMC-4
Newark, NJ 07107
(800) 362-0071
(973) 972-0410
(973) 972-0399 (fax)
✉ortegaes@umdnj.eou
http://www.pedhivaid.org
1,2,4,7; *Spanish/Creole materials*

ALAGILLE SYNDROME

See also: *Heart Disorders; Liver Disorders*

Alagille Syndrome Alliance
10630 SW Garden Park Pl.
Tigard, OR 97223
(503) 639-6217
✉alagille@teleport.com
http://www.alagille.org
1,2,3,4,6,

ALANINURIA

See: *Lactic Acidosis; Acidemia, Organic*

ALBINISM & HYPOPIGMENTATION

See also: *Visual Impairments*

NOAH (National Organization for Albinism and Hypopigmentation)
PO Box 959
E. Hampstead, NH 03826-0959
(800) 473-2310
(603) 887-6049 (phone/fax)
✉webmaster@albinism.org
http://www.albinism.org/
1,2,3,4,5,6,8,9; *Spanish materials*

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

ALBRIGHT SYNDROME
See: *Growth Disorders*

ALGONEURODYSTROPHY
See: *Reflex Sympathetic Dystrophy Syndrome*

ALLERGY
See: *Asthma & Allergy, Food Allergy, Latex Allergy*

ALLERGY, FOOD
See: *Food Allergy*

ALLERGY, LATEX
See: *Latex Allergy*

ALOPECIA AREATA NATIONAL

National Alopecia Areata Foundation
PO Box 150760
San Rafael, CA 94915-0760
(415) 456-4644
(415) 456-4274 (fax)
✉info@naaf.org
http://www.naaf.org
1,2,3,4,5,6,7,8,9; Spanish *materials*

ALOPECIA UNIVERSALA-ONYCHODYSTROPHY-TOTAL VITILIGO
See: *Ectodermal Dysplasias, Vitiligo*

ALOPECIA-ANOSMIA-DEAFNESS-HYPOGONADISM
See: *Ectodermal Dysplasias*

ALOPECIA-ONYCHODYSPLASIA-HYPOHIDROSIS
See: *Ectodermal Dysplasias*

ALPHA-1-ANTITRYPSIN (AAT) DEFICIENCY
See also: *Liver Disorders, Lung Diseases*

Alpha-1 Antirypsis Deficiency National Association
8120 Penn Ave. South, Ste. 549
Minneapolis, MN 55431
(800) 521-3025
(952) 703-9975
(952) 703-9977 (fax)
✉info@alpha1.org
http://www.alpha1.org
1,2,3,4,5,6,7,9

ALPHA-GALACTOSIDASE DEFICIENCY
See: *Fabry Disease*

ALPHA THALASSEMIA MENTAL RETARDATION SYNDROME, X-LINKED

Alpha Thalassemia Mental Retardation Syndrome (ATR-X) Support Group
http://www.groups.yahoo.com/group/atr-x
c/o International Rare Disease Support Network (IRDSN)
David Hughes,
President/Founder
1437 Cool Springs Dr,
Mesquite, TX USA 74181
(469) 726-0380
✉ATRX@rarediseasesupport.org
✉supportgroups@home.com
✉irdsn@rarediseasesupport.org
http://www.raredisorders.com

ALPORT SYNDROME
See: *Hearing Impairments; Kidney Diseases, Hereditary, Vision Impairments*

ALSTROM SYNDROME
See: *Diabetes Mellitus, Hearing Impairments, Kidney Disorders, Retinitis Pigmentosa, Visual Impairments*

ALTERNATING HEMIPLEGIA
See: *Hemiplegia, Alternating*

AMELOCEREBROHYPHOHIDROTIC SYNDROME
See: *Ectodermal Dysplasias*

AMELOONYCHOHYPHOHIDROTIC DYSPLASIA
See: *Ectodermal Dysplasias*

AMNIOTIC BANDS
See: *Craniofacial Disorders*

AMPUTATION
See also: *Limb Disorders*

American Amputee Foundation
PO Box 250218
Little Rock, AR 72225
(501) 666-2523
(501) 666-8367 (fax)
2,3,4,5,7,9

Amputee Coalition of America
900 E. Hill Ave., Ste. 285
Knoxville, TN 37915-2568
(888) AMP-KNOW (267-5669)
(865) 524-8772
(865) 525-7917 (fax)
✉acainfo@amputee-coalition.org
http://www.amputee-coalition.org
1, *(newsletter for support grp leaders)* ***2,3,5,*** *(nat'l support groups)* ***6,7;*** *Spanish materials*

National Amputation Foundation
38-40 Church St.
Malvern, NY 11565
(516) 887-3600
(516) 887-3667 (fax)
✉amps76@aol.com
http://www.nationalamputation.org
1,2,3,4,7,9

AMSTERDAM DWARF SYNDROME OF DE LANGE
See: *Cornelia de Lange Syndrome*

AMYLO-1, 6-GLUCOSIDASE DEFICIENCY
See: *Glycogen Storage Diseases; Muscular Dystrophy*

AMYLOPECTINOSIS
See: *Glycogen Storage Diseases*

AMYOPLASIA, CONGENITA
See: *Arthrogryposis Multiplex Congenita*

ANAL ATRESIA
See: *Anorectal Malformations*

ANAL STENOSIS
See: *Anorectal Malformations*

ANDERSEN DISEASE
See: *Glycogen Storage Diseases*

ANDERSON-FABRY DISEASE
See: *Fabry Disease*

ANDERSON-WARBURG SYNDROME
See: *Norrie Disease*

ANEMIA, APLASTIC
See: *Anemia, Fanconi; Bone Marrow Transplant*

Aplastic Anemia and Myelodysplasia Association of Canada
22 Aikenhead Rd
Etobicoke, ON CAN M9R 2Z3
(416) 235-0468
(519) 235-1756 (fax)
http://www.aplastic.ualberta.ca
1,2,4,7,8,9

Aplastic Anemia MDS International Foundation, Inc.
PO Box 613
Annapolis, MD 21404-0613
(800) 747-2820
(410) 867-0240 (fax)
✉aamdsoffice@aol.com
http://www.aamds.org
1,2,3,5,6,8,9

ANEMIA, AREGENERATIVE
See: *Anemia, Aplastic*

ANEMIA, COOLEY
See: *Cooley Anemia*

ANEMIA, DIAMOND BLACKFAN
See also: *Anemia Aplastic, Anemia Fanconi, Autoimmune Disorders*

Diamond Blackfan Anemia Registry
1 Gustave Levy Pl.
Box 1208
New York, NY 10029
(212) 241-6031
(212) 360-6921 (fax)

ANEMIA, ERYTHROBLASTOTIC
See: *Cooley Anemia*

ANEMIA, FANCONI
See also: *Anemia, Aplastic; Heart Disorders; Kidney Disorders; Leukemia*

Fanconi Anemia Research Fund/Support Group
(800) 828-4891 (family support only)
(541) 687-4658
(541) 687-0548 (fax)
✉info@fancani.org
http://www.fanconi.org
1,2,3,4,5,6,7,8,9; *Spanish/Portugese/French materials*

ANEMIA, HEMOLYTIC
See: *Cooley Anemia*

ANEMIA, HYPOPLASTIC
See: *Anemia, Aplastic*

ANEMIA, MEDITERRANEAN
See: *Cooley Anemia*

ANEMIA, REFRACTORY
See: *Anemia, Aplastic*

ANEMIA, TARGET CELL
See: *Cooley Anemia*

ANEMIA, TOXIC PARALYTIC
See: *Anemia, Aplastic*

ANGELMAN SYNDROME
See also: *Epilepsy*

Angelman Syndrome Foundation
414 Plaza Dr., Ste. 209
Westmont, IL 60559-5507
(800) 432-6435
(630) 734-9267
(630) 655-0391 (fax)
✉info@angelman.org
http://www.angelman.org
1,2,3,4,5,6,7,8,9; *Internet mail list subscribe by sending e-mail to: listserv@ucsd.edu*

Canadian Angelman Syndrome Society
PO Box 37
Priddis, AB CAN, T0L 1W0
(403) 931-2415 (voice/fax)
✉cass@cadvision.com
http://ugel.phys.ualberta.ca/cass
1,2,3,5,6,9; *French materials*

ANGIO-OSTEOHYPERTROPHY SYNDROME
See: *Klippel-Trenaunay Syndrome*

ANGIOKERATOMA CORPORIS DIFFUSUM
See: *Fabry Disease*

ANGIOMATOSIS RETINA
See: *Von Hippel-Lindau Syndrome*

ANIRIDIA
See also: *Visual Impairments, WAGR Syndrome*

The Canadian Foundation for Aniridia Research
3780 Verdun Ave., Ste. 2
Montreal, QUE CAN H4G 1K6
(888) 650-5555 (Can&USA)
(514) 845-5555
(514) 845-5004(FAX)
✉info@generations.net
http://www.anindia.org

ANKYLOSING SPONDYLITIS, JUVENILE
See: *Arthritis*

ANOPHTHALMIA
See also: *Visual Impairments*

International Children's Anophthalmia Network
5501 Old York Rd.
Philadelphia, PA 19141
(800) 580-4226
(215) 456-2356 (fax)
✉aemcgenetics2@hotmail.com
http://www.ioi.com/ca
1,2,3,4,6,9

ANORECTAL MALFORMATIONS
See also: *Intestinal Pseudo-Obstruction Syndrome*

Pull-Thru Network
4 Woody Ln.
Westport, CT 06880
(203) 221-7350
(203) 221-9212 (fax)
✉pullthrunw@aol.com
http://www.pullthrough.org
1,2,3,4,9

ANOREXIA NERVOSA
Includes bulimia nervosa and binge eating disorder

American Anorexia Bulimia Association, Inc.
http://www.aabainc.org
2,3,4,5

National Association of Anorexia Nervosa and Related Disorders
PO Box 7
Highland Park, IL 60035
(847) 831-3438
(847) 433-4632 (fax)
✉anad20@aol.com
http://www.anad.org
2,3,4,5,6,7

APECED SYNDROME
See: *Ectodermal Dysplasia, Hypoparathyroidism*

APERT SYNDROME
See also: *Craniofacial Disorders*

Apert Syndrome Pen Pal Network
PO Box 115
Providence, RI 02901
(401) 454-4849
2, 3,

APHASIA, ACQUIRED
See also: *Brain Injury, Stroke*

National Aphasia Association
156 Fifth Ave., Ste. 707
New York, NY 10010
(800) 922-4622
(212) 989-7777 (fax)
✉naa@aphasia.org
http://www.aphasia.org
1,2,3,4,5

APLASTIC ANEMIA
See: *Anemia, Aplastic*

APNEA, INFANTILE
See: *Apnea, Sleep*

APNEA, SLEEP

American Sleep Apnea Association
1424 K St. NW Ste. 302
Washington, DC 20005
(202) 293-3656
✉asaa@sleepapnea.org
http://sleepapnea.or
1,2,4

APRAXIA
See also: *Learning Disabilities*

C.H.E.R.A.B. Foundation, Inc.
(Communication Help, Education, Research, Apraxia Base Foundation)
Lisa Geng, President,
657 Valley Rd. Box 339
Gillette, NJ 07933
(732) 871-6013
✉kiddietalk@yahoo.com
http://www.apraxia.cc/

The Childhood Apraxia of Speech Association
123 Eisele Rd.
Cheswick, PA 15024
(412) 767-6589
(412) 767-0534 (fax)
✉helpdesk@apraxia.org
http://www.apraxia.org
1,2,4,7

AQUEDUCTAL STENOSIS
See: *Hydrocephalus*

ARACHNODACTYLY
See: *Marfan Syndrome*

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

AREGENERATIVE ANEMIA
See: *Anemia, Aplastic*

ARGINASE DEFICIENCY
See: *Urea Cycle Disorders*

ARGININOSUCCINASE DEFICIENCY
See: *Urea Cycle Disorders*

ARGININOSUCCINIC ACID SYNTHETASE DEFICIENCY
See: *Urea Cycle Disorders*

ARGININOSUCCINIC ACIDURIA
See: *Urea Cycle Disorders*

ARNOLD CHIARI MALFORMATION
See also: *Syringomyelia*

National Institute of Neurological Disorders (NIH)
31 Center Dr., MSC 2540
Bldg. 31, Rm. 8A16
(800) 352-9424
(301) 496-5751
(301) 402-2186 (fax)
http://www.ninds.nih.gov/

ARTERIOHEPATIC DYSPLASIA
See: *Alagille Syndrome*

ARTERIOVENOUS MALFORMATIONS (AVMS)
See: *Epilepsy; Stroke; Vascular Malformations*

ARTHRO-OPTHALMOPATHY
See: *Stickler Syndrome*

ARTHRITIS

American Juvenile Arthritis Organization
1330 W. Peachtree St.
Atlanta, GA 30309
(800) 283-7800
(404) 872-7100
(404) 872-9559 (fax)
http://www.arthritis.org
1,2,3,4,5,6,7,8; *Spanish materials*

Arthritis Society
#1700, 393 University Ave.
Toronto, ON CAN M5G 1E6
(800) 321-1433(Canada only)
(416) 979-7228
(416) 979-8366 (fax)
✉nkent@arthritis.ca
http://www.arthritis.ca
2,5,7,8; *French materials*

National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse (NIAMS)
1 AMS Circle
Bethesda, MD 20892-3675
(301) 495-4484
(877) 22-NIAMS (226-4267)
(free call)
(301) 565-2966 (TDD)
(301) 718-6366 (fax)
http://www./nih.gov/niams/
2,4

ARTHROCHALASIS MULTIPLEX CONGENITA
See: *Ehlers-Danlos Syndrome*

ARTHROGRYPOSIS MULTIPLEX CONGENITA
See also: *Growth Disorders; Muscular Dystrophy*

AVENUES: A National Support Group for Arthrogryposis Multiplex Congenita
PO Box 5192
Sonora, CA 95370
(209) 928-3688
✉avenues@sonnet.com
http://www.sonnet.com/avenues
1,2,3

ASCENDING PARAYLSIS
See: *Guillain-Barré Syndrome*

ASPERGER SYNDROME
See: *Autism*

ASTHMA
See: *Asthma & Allergy*

ASTHMA & ALLERGY
See also: *Food Allergy; Latex Allergy; Lung Diseases*

Allergy & Asthma Network Mothers of Asthmatics, .
2751 Prosperity Ave., Ste 150
Fairfax, VA 22031-4397
(800) 878-4403 (toll Free)
(703) 6419595 (local)
(703) 573-7794 (fax)
✉info@aanma.org
http://www.aanma.org
1,2,3,4,7

Asthma and Allergy Foundation of America
1233 20th Street, NW, Ste. 402
Washington, DC 20036
(800) 727-8462
(202) 466-7643
(202) 466-8940 (fax)
✉info@aafa.org
http://www.aafa.org
1,2,3,4,5,6,7,8; *Spanish materials*

Asthma Society of Canada
130 Bridgeland Ave., Ste. 425
Toronto, ON CAN M6A 1Z4
(416) 787-4050
(416) 787-5807 (fax)
✉info@asthma.ca
http://www.asthma.ca
1,2,8; *patient education*

ATAXIA
See also: *Friedreich Ataxia*

National Ataxia Foundation
2600 Fernbrook Ln., Ste. 119
Minneapolis, MN 55447-4752
(763) 553-0020
(763) 553-0167 (fax)
✉naf@mr.net
http://www.ataxia.org
1,2,3,4,5,6,8

ATAXIA, FAMILIAL
See: *Ataxia; Friedreich Ataxia*

ATAXIA, FRIEDREICH
See: *Ataxia; Friedreich Ataxia*

ATAXIA, SPINOCEREBELLAR
See: *Ataxia; Friedreich Ataxia*

ATAXIA, TELANGIECTASIA
See also: *Ataxia; Autoimmune Disorders; Cancer; Immune Disorders; Leukemia*

Ataxia Telangiectasia Children's Project
668 South Military Trail
Deerfield Beach, FL 33442
(800) 543-5728
(954) 481-6611
(954) 725-1153 (fax)
✉info@atcp.org
http://www.atcp.org
1,2,3,4,6,8,9; *Spanish materials*

ATAXIA WITH LACTIC ACIDOSIS II
See: *Ataxia; Lactic Acidosis; Mitochondrial Disorders*

ATRESIA
See: *Microtia*

ATRIAL SEPTAL DEFECTS
See: *Heart Disorders*

ATROPHIA BULBORUM HEREDITARIA
See: *Norrie Disease*

ATTENTION DEFICIT DISORDER

The ADHD Challenge
PO Box 488
West Peabody, MA 01985-7277
(800) 233-2322
1,2,4

Learning Disabilities AD-IN: Attention Deficit Information Network
475 Hillside Ave.
Needham, MA 02494-1278
(781) 455-9895
(781) 444-5466 (fax)
✉adin@gis.net
http://www/.addinfonetwork.org
2,3,4,5,6,9

CHADD-Canada, Inc.-Children and Adults with Attention Deficit Disorder
1376 Bank St.
Ottawa ON, CAN K1H 1B3
(613) 731-1209
(613) 257-1563 (fax)
✉chaddcanad@hotmail.com
http://www.chadd.org
http://www.members.tripod.com/~chaddcanada/index.html
1,2,3,5,6,9; *Spanish materials*

CHADD: Children and Adults with Attention Deficit Hyperactivity Disorders
8181 Professional Pl., Ste. 201
Landover, MD 20785
(800) 233-4050
(301) 306-7070
(301) 306-7090 (fax)
✉national@chadd.org
http://www.chadd.org
1,2,3,5,6,7,9; *Spanish materials*

National ADD Association
1788 2nd St., Ste. 200
Highland Pk, IL 60035
(847) 432-ADDA (2332)
http://www.add.org
✉mail@add.org
1,2,4,6

ATTENUATED ADENOMATOUS POLYPOSIS COLI
See: Hereditary Colon Cancer

AUDITORY NEUROPATHY
See: *Kernicterus*

AURICULO-OCULO-VERTEBRAL SYNDROME
See: *Goldenhar Syndrome*

AUTISM
See also: *Autism and Sensory Impairments*

Asperger Syndrome Coalition of the United States
PO Box 49267
Jacksonville, FL 32240-9267
(904) 745-6741
✉info@asc-us.org
http://www.asperger.org
2,3

Autism Independent UK
199/201 Blanford Ave
Kettering, Northants NN16 9AT
United Kingdom
01536 523274 (phone/fax)
✉autism@rmplc.co.uk
http://www.autismuk.com

Autism National Committee
PO Box 6175
N. Plymouth, MA 02362-6175
(781) 648-1813 (phone/fax)
http://www.autcom.org
1,2,6,7

Autism Research Institute
4182 Adams Ave.
San Diego, CA 92116
(619) 281-7165
(619) 563-6840 (fax)
http://www.autism.com/autism
1,2,4,6,9

Autism Resources
http://www.unc.edu/~cory/autism-info
2,3,4,7,9

Autism Society of America
7910 Woodmont Ave., Ste. 300
Bethesda, MD 20814-3067
(800) 328-8476
(301) 657-0881
(301) 657-0869 (fax)
http://www.autism-society.org/
1,2,5,6,7,8,9

Autism Society of Canada
129 Yorkville Ave., #202
Toronto, ON CAN M5R 1C4
(416) 922-0302
(416) 922-1032 (fax)
1,2,4,7; *French materials*

Center for Study of Autism
PO Box 4538
Salem, OR 97302
(503) 363-9110 (voice/fax)
✉sait@teleport.com
http://www.autism.org/
2,6

MAAP Services, Inc.
PO Box 524
Crown Point, IN 46308
(219) 662-1311
(219) 662-0638 (fax)
✉chart@netnitco.net
http://www.maapservices.org
1,2,5,6

National Autism Hotline/Autism Services Center
605 Ninth St., Prichard Bldg.
PO Box 507
Huntington, WV 25710-0507
(304) 525-8014
(304) 525-8026 (fax)
2,3,5,7; *Spanish/Italian/French materials*

The New Jersey Center for Outreach and Services for the Autism Community Inc. (COSAC)
1450 Parkside Ave., Ste. 22
Ewing, NJ 08638
(800) 4-AUTISM (NJ only)
(609) 883-8100
(609) 883-5509 (fax)
✉information@njcosac.org
http://www.njcosac.org
1,2,4

AUTISM AND SENSORY IMPAIRMENTS
See also: *Hearing Impairments; Visual Impairments*

The Autism Network for Hearing & Visually Impaired Persons
c/o Dolores and Alan Bartel
7510 Oceanfront Ave.
Virginia Beach, VA 23451
(757) 428-9036
(757) 428-0019 (fax)
3,4,6,7,9

CAN (Cure Autism Now)
5455 Wilshire Blvd., Ste. 715
Los Angeles, CA 90036
(888) 8-AUTISM (288476)
(323) 549-0500
(323) 549-0547 (fax)
✉info@cureautismnow.org
http://www.canfoundation.org

Indiana Resource Center for Autism (IRCA)
Indiana Institute on Disability and Community at Indiana University Bloomington
2853 E. Tenth St.
Bloomington, IN 47408-2696
(812) 855-6508
(812) 855-9396 (TDD)
(812) 855-9630 (fax)
✉prattc@indiana.edu
http://www.isdd.indiana.edu/~irca
1,2,4,6

The National Alliance for Autism Research
99 Wall St., Research Park
Princeton, NJ 08540
(888) 777-NAAR (5227)
(609) 430-9160
(609) 430-9163 (fax)
✉naar@naar.org
http://www.naar.org
1,2,8

On-line Asperger's Syndrome Information and Support (OASIS)
✉bkirby@udel.edu
http://www.udel.edu/bkirby/asperger
2,3

TEACCH
310 Medical School Wing E
University of North Carolina at Chapel Hill/CB #7180
Chapel Hill, NC 27599-7180
(919) 966-2174
(919) 966-4127 (fax)
✉teacch@unc.edu
http://www.teacch.com
2,4,5,6,9

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

Yale Program for Autism, Prader-Willi Syndrome, and Williams Syndrome
Yale Child Study Center
230 S. Frontage Rd.
PO Box 207900
New Haven, CT 06520-7900
(203) 785-7923
(203) 785-7611 (fax)
✉devdis.clinic@yale.edu
http://info.med.yale.edu/chldstdy wspws
2,4

AUTOIMMUNE DISORDERS

See also: Immune Disorders; Vitiligo

American Autoimmune Related Diseases Association
22100 Gratiot Ave.
East Detroit, MI 48021
(800) 598-4668
(810) 776-3900
(810) 776-3903 (fax)
✉aarda@aol.com
http://www.aarda.org
1,2,4,5, *(Local Contacts)* ***6,7,8***

AUTOIMMUNE MYOCARDITIS

See: Autoimmune Disorders

B12 METABOLISM; INBORN ERROR OF

See: Cobalamin (B12) Defiency

BAISCH SYNDROME

See: Ectodermal Dysplasias

BALANCE DISORDERS & DIZZINESS

See also: Vestibular Disorders

EAR Foundation
1817 Patterson St.
Nashville, TN 37203-2110
(800) 545-4327 (voice/TDD)
(615) 329-7807
(615) 329-7935 (fax)
✉ear@earfoundation.org
http://www.earfoundation.org
1,2

BANNAYAN, RUVALCABA, RILEY-SMITH SYNDROME

See: Sotos Syndrome

BARDET-BIEDL SYNDROME

See: Laurence-Moon-Bardet-Biedl Syndrome

BARTH SYNDROME

See also: Heart Disorders; Neutropenia; Short Stature

The Barth Syndrome Foundation, Inc.
PO Box 974
Perry, FL 32348
(850) 223-1128
(402) 421-1926
✉ postmaster@barthsyndrome.org/
http://www.barthsyndrome.org

BATTEN DISEASE

Batten Disease Support and Research Association
120 Humphries Dr., Ste 2
Reynoldsburg, OH 43068
(800) 448-4570
(740) 927-4298
✉bdsra1@bdsra.com
http://www.bdsra.org
1,2,3,4,5,6,7,8, 9; *Spanish/Portugese/German/French materials*

Batten Disease Support and Research Association, Canadian Chapter
c/o Bev Maxim
17 Bell St.
Regina, SK CAN S4S 4B7
(306) 789-9047
(800) 400-8968
✉bdsra1@bdsra.org
http://www.bdsra.org
1,2,3,4,5,6,7,8,9

National Batten Disease Registry
1050 Forest Hill Rd.
Staten Island, NY 10314-6399
(800) 952-9628
(718) 494-5201
(718) 982-6346 (fax)
✉edith.docktee@omr.state.ny.us
2,4,5,9; *genetic counseling, diagnostic testing*

BATTEN-MAYOU SYNDROME

See: Batten Disease

BATTEN-SPIELMEYER-VOGT DISEASE

See: Batten Disease

BBB SYNDROME

See: Opitz Syndrome

BBBG SYNDROME

See: Opitz Syndrome

BECKER MUSCULAR DYSTROPHY

See: Muscular Dystrophy

BECKWITH-WIEDEMANN SYNDROME

Beckwith-Wiedemann Support Network
2711 Colony Rd.
Ann Arbor, MI 48104
(800) 837-2976 (parents only)
(734) 973-0263
(734) 973-9721 (fax)
✉A800BWSN@aol.com
http://www.beckwith-wiedemann.org
1,2,3,4,6

BEDWETTING

See: Incontinence

BEHCET'S DISEASE

See: Autoimmune Disorders

BELL'S PALSY

Bell's Palsy Research Foundation
9121 E. Tanque Verde
Ste. 105-286
Tuscon, AZ 85749
(520) 749-4614
(520) 749-0489 (fax)
✉BellsPalsy@aol.com
2,3,4,8,9

BENIGN CONGENITAL HYPOTONIA

See: Spinal Muscular Atrophy

BERGER DISEASE

See: Kidney Disorders

BETA THALASSEMIA MAJOR

See: Cooley Anemia

BEUREN SYNDROME

See: Williams Syndrome

BIOTINIDASE DEFICIENCY

See: Metabolic Disorders

BIRTHMARK

See: Nevi, Giant Congenital

BLEEDING DISORDERS

See: Hemophilia

BLEPHAROPHIMOSIS, PTOSIS, EPICANTHUS INVERSUS SYNDROME (BPES)

See also: Craniofacial Disorders

Blepharophimosis, Ptosis, Epicanthus Inversus Family Network
c/o Lynne Schauble
SE 820 Meadow Vale Dr.
Pullman, WA 99163
(509) 332-6628
✉lschauble@gocougs.wsu.edu
1,2,3,9

BLEPHAROSPASM

See: Dystonia

BLINDNESS

See: Visual Impairments

BLOCH-SULZBERGER SYNDROME

See: Incontinentia Pigmenti

BLOOM SYNDROME

See: Cancer; Immune Disorders; Growth Disorders; Short Stature

BONE MARROW TRANSPLANT

See also: Cancer

Blood & Marrow Transplant Information Network
2900 Skokie Valley Rd., Ste B
Highland Park, IL 60035
(888) 597-7674
(847) 433-3313
(847) 433-4599 (fax)
✉help@bmtinfonet.org
http://wwwbmtinfonet.org
1,2,3,9; *legal referral for insurance problems*

BONE TUMOR-EPIDERMOID CYST-POLYPOSIS

See: Colon Cancer, Hereditary; Polyposis

BONNEVIE-ULRICH SYNDROME

See: Turner Syndrome

BOOK SYNDROME

See: Ectodermal Dysplasias

BOURNEVILLE PRINGLE SYNDROME

See: Tuberous Sclerosis

BOWEL DYSFUNCTION/ IRRITABLE BOWEL SYNDROME

See also: Gastrointestinal Disorders

International Foundation for Functional Gastrointestinal Disorders (IFFGD)
PO Box 170864
Milwaukee, WI 53217
(888) 964-2001
(414) 964-1799
(414) 964-7176 (fax)
✉IFFGD@iffgd.org
http://www.iffgd.org
1,2,4,6,7,9

BRACHIAL PLEXUS INJURY

See: Erb Palsy

BRACHMANN-DE LANGE SYNDROME

See: Cornelia de Lange Syndrome

BRAIN ATTACK

See: Stroke

BRAIN INJURY

See also: Aphasia, Acquired

Brain Injury Association
105 N. Alfred St.
Alexandria, VA 22314
(800) 444-6443 (family helpline)
(703) 236-6000
(703) 236-6001 (fax)
✉familyhelpline@biausa.org
http://www.biaUSA.org
1,2,3,4,5,6,7,8; *Spanish materials*

Coma Recovery Association, Inc.
807 Carman Avenue
Westbury, NY 11590
(516) 997-1826
(516) 997-1613 (fax)
http://www.comarecovery.org
1,2,3,4,5,6,7

BRAIN STEM MALFORMATIONS

See: Arnold-Chiari Malformation; Joubert Syndrome; Syringomyelia

BRAIN TUMORS

See also: Acoustic Neuroma; Brain Injury; Cancer; Epilepsy; Pituitary Disorders/Tumors; Von Hippel-Lindau Syndrome

American Brain Tumor Association
2720 River Rd., Ste. 146
Des Plaines, IL 60018
(800) 886-2282
(847) 827-9910
(847) 827-9918 (fax)
✉info@abta.org
http://www.abta.org
1,2,3,4,6,7,8; *Spanish materials*

Brain Tumor Foundation for Children, Inc.
1835 Savoy Dr., Ste. 316
Atlanta, GA 30341
(770) 458-5554
(770) 458-5467 (fax)
✉btfc@bellsouth.net
http://www.btfcgainc.org
1,2,3,4,5,6,8; *materials*

Brain Tumor Foundation of Canada
650 Waterloo St., Ste. 100
London, ON CAN N6B 2R4
(800) 265-5106
(519) 642-7755
(519) 642-7192 (fax)
✉info@btfc.org
http://www.btfc.org
1,2,3,4,6,8,9; *French materials*

Brain Tumor Society
124 Watertown St., Ste. 3-H
Watertown, MA 02472
(800) 770-8287
(617) 924-9997
(617) 924-9998 (fax)
✉info@tbts.org
http://www.tbts.org
1,2,3,6,7,8

Children's Brain Tumor Foundation
274 Madison Ave., Ste. 1301
New York, NY 10016
(212) 448-9494
(866) CBT-HOPE (228-4673) (Toll Free)
(212) 448-1022 (fax)
✉cbtfny@aol.com
http://www.cbtf.org
1,2,3,4; *Referrals to national Resources* ***6,7,8***

Making Headway Foundation, Inc
115 King St
Chappaqua, NY 10514-3460
(914) 238-8384,
(914) 238-1693 (fax
✉mhf@makingheadway. org
http://www.makingheadway.org
1,8; *family support group; one-to-one counseling; learning assistance Spinal Cord Tumors, Seminars*

National Brain Tumor Foundation
Cathy Clarence
414 Thirteenth St., Ste. 700
Oakland, CA 94612-2603
(800) 934-2873 (info line)
(510) 839-9777
(510) 839-9779 (fax)
✉nbtf@braintumor.org
http://www.braintumor.org
1,2,3,4,6,8

BRANCHED CHAIN KETONURIA

See: Maple Syrup Urine Disease

BRANCHER DEFICIENCY

See: Glycogen Storage Diseases

BRANCHIO-OTO-RENAL SYNDROME

See: Craniofacial Disorders; Hearing Impairments, Kidney Disorders

BRITTLE BONE DISEASE

See: Osteogenesis Imperfecta

BROAD THUMB-HALLUX SYNDROME

See: Rubinstein-Taybi Syndrome

BURKE SYNDROME

See: Shwachman Syndrome

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

BURNS

Phoenix Society for Burn Survivors
1840 Wealthy South East,
Ste 215
East Grand Rapids, MI 49506
(800) 888-2876
(616) 458-2773
(616) 458-2831 (fax)
✉info@phoenix-society.org
http://www.phoenix-society.org
1,2,3,4,5,6,7,9

CALLOSAL AGENESIS

See: *Agenesis of the Corpus Callosum; Aicardi Syndrome*

CAMARENA SYNDROME

See: *Ectodermal Dysplasias*

CAMPTOMELIC SYNDROME

See: *Growth Disorders; Short Stature*

CANAVAN DISEASE

See also: Leukodystrophy; Tay-Sachs Disease

The Canavan Research Foundation
Fairwood Professional Building
New Fairfield, CT 06812
(203) 746-2436
(203) 746-3205 (Fax)
✉canavan_research@hotmail.com
http://www.canavan.org/
2,3,7,8,9

CANCER

See also: Bone Marrow Transplant; Brain Tumors; Colon Cancer, Hereditary; Leukemia; Polyposis

American Cancer Society
1599 Clifton Rd. NE
Atlanta, GA 30329-4251
(800) 227-2345
(404) 320-3333
(404) 982-3676 (fax)
http://www.cancer.org
2,4,5,7,8; *Spanish materials*

Canadian Cancer Society
10 Alcorn Ave, Ste. 200
Toronto, ON CAN M4V 3B1
(416) 961-7223
(416) 961-4189 (fax)
✉ccs@cancer.ca
http://www.cancer.ca
1,2,3,4,5,7,8; *French materials*

Candlelighters Childhood Cancer Foundation
3910 Warner St.
Kensington, MD 20895
(800) 366-2223
(301) 962-3520 (phone/fax)
✉info@candlelighters.org
http://www.candlelighters.org
1,2,3,4,5,7; Survivors of Childhood Cancer program; speakers bureau

Childhood Cancer Foundation-Candlelighters Canada
55 Eglinton Ave E, Ste. 401
Toronto, ON CAN M4P 1G8
(800) 363-1062 (Canada only)
(416) 489-6440
(416) 489-9812 (fax)
✉staff@candlelighters.ca
http://www.candlelighters.ca
1,2,3,4,5,6,7; 8, *French materials*

CANCER; BRAIN

See: *Brain Tumors*

CANCER; GASTROINTESTINAL

See: *Colon Cancer, Hereditary; Polyposis*

CARBAMYL PHOSPHATE SYNTHETASE (CPS) DEFICIENCY

See: *Urea Cycle Disorders*

CARDIAC DISORDERS

See: *Heart Disorders*

CARDIO-FACIO-CUTANEOUS SYNDROME

See: *Heart Disorders; Ichthyosis*

CAREY SYNDROME

See: *Ectodermal Dysplasias*

CARNITINE DEFICIENCY SYNDROMES

See also: Acidemia, Organic; Fatty Oxidation Disorder; Mitochondrial Disorders, Muscular Dystrophy

CARNITINE PALMITYL TRANSFERASE DEFICIENCY

See: *Acidemia, Organic; Fatty Oxidation Disorder; Mitochondrial Disorders, Muscular Dystrophy*

CARPENTER SYNDROME

See: *Craniofacial Disorders*

CARTILAGE-HAIR HYPOPLASIA

See: *Dwarfism; Growth Disorders, Short Stature*

CARTILAGNOUS ENCHONDROSES, MULTIPLE

See: *Ollier Disease*

CAT'S CRY SYNDROME

See: *Cri Du Chat Syndrome*

CAUSALGIA SYNDROME

See: *Reflex Sympathetic Dystrophy Syndrome*

CELIAC DISEASE

See also: Celiac Sprue; Gluten Intolerance

Canadian Celiac Association
5170 Dixie Road,Suite 204
Mississauga. ON CAN L4W 1E3
(800) 363-7296 (Canada only)
(905) 507-6208
(905) 507-4673 (fax)
celiac@look.ca
http://www.celiac.ca
1,2,4,5,6,7,8; *French materials*

Celiac Disease Foundation
13251 Ventura Blvd.,
#1 Studio City
Los Angeles, CA 91604-1838
(818) 990-2354
(818) 990-2379 (fax)
✉cdf@celiac.org
http://www.celiac.org
1,2,3,4,7,9

CELIAC SPRUE

See also: Celiac Disease; Gluten Intolerance

American Celiac Society
59 Crystal Ave
West Orange, NJ 07052-3570
(973) 325-8837
(973) 669-8808 (fax)
✉amerceliacsoc@netscape.net
1,2,4,5,6; *speakers bureau*

American Celiac Society Dietary Support Coalition
59 Crystal Ave
West Orange, NJ 07052
(973) 325-8837
(973) 669-8808 (fax)
✉bentleac@umdnj.edu
1,2,3,4,5,6,7,8; *speakers bureau*

CENTRAL HYPOVENTILATION SYNDROME, CONGENITAL

See also: Apnea, Sleep; Intestinal Pseudo-Obstruction Syndrome; Ventilator Use

Congenital Central Hypoventilation Syndrome Family Support Network
71 Maple St.
Oneonta, NY 13820
✉vanderlaanm@hartwick.edu
1,2,3,6,7,9

CEREBELLAR HYPOPLASIA

See: *Joubert Syndrome*

CEREBELLAR VERMIS APLASIA/HYPOPLASIA

See: *Joubert Syndrome*

CEREBELLO-OCULOCUTANEOUS TELANGIECTASIA

See: *Ataxia Telangiectasia*

CEREBELLORETINAL HEMANGIOBLASTOMATOSIS

See: *Von Hippel-Lindau Syndrome*

CEREBRAL GIGANTISM

See: *Sotos Syndrome*

CEREBRAL PALSY

Ontario Federation for Cerebral Palsy
1630 Lawrence Ave. W.,
Ste. 104
Toronto, ON CAN M6L 1C5
(416) 244-9686
(877) 244-9686 (Toll Free)
(416) 244-6543 (fax)
✉ofcp@ofcp.on.ca
http://www.ofcp.on.ca
1,2,3,4,6; *Provincial conferences 7, Provincial Adovcacy efforts ,9; French materials*

United Cerebral Palsy Associations
1660 L St. NW, Ste. 700
Washington, DC 20036-5602
(800) 872-5827
(202) 776-0406
(202) 973-7197 (TDD)
(202) 776-0414 (fax)
✉national@ucp.org
http://www.ucp.org
1,2,3,4,5,6,7,8; *Spanish materials, provides direct services through 130 affiliate programs*

United Cerebral Palsy of NYC
80 Maiden Ln., 8th Fl.
New York, NY 10038-4811
(212) 683-6700
✉infoucp@aol.com
http://www.ucpnyc.org
1,2,3,4,5,6,7,8

CEREBROOCULORENAL DYSTROPHY

See: *Lowe Syndrome*

CEREBROSIDE LIPIDOSIS

See: *Gaucher Disease*

CEREBROTENDINOUS

See: *Leukodystrophy; Tay-Sachs Disease*

CHAGAS' DISEASE

See: *Autoimmune Disorders*

CHALASODERMIA

See: *Connective Tissue Disorders*

CHANARIN-DORFMAN SYNDROME

See: *Ichthyosis*

CHANDS ASSOCIATION

See: *Ectodermal Dysplasias*

CHARCOT-MARIE-TOOTH DISEASE

See also: Ataxia; Muscular Dystrophy; Myelin Disorders

Charcot-Marie-Tooth Association
2700 Chestuct St.
Chester, PA 19013
(800) 606-2682
(610) 499-9264
(610) 499-9267 (fax)
✉cmtassoc@aol.com
http://www.charcot-marie-tooth.org
1,2,4,5,7,6,8,9; *Spanish materials*

Charcot-Marie-Tooth International
1 Springbank Dr.
St Catharines, ON CAN L2S 2K1
(905) 687-3630
(905) 687-8753 (fax)
✉cmtint@vaxxine.com
http://www.cmtint.org
1,2,3,5,7,9; *Scholarship program for members.*

CHARGE ASSOCIATION

See also: Heart Disorders; Hearing Impairments; Velo-Cardio-Facial Syndrome; VACTERL Association; Visual Impairments

CHARGE Syndrome Foundation
2004 Parkade Blvd.
Columbia, MO 65202-3121
(800) 442-7604
(573) 499-4694 (voice/fax)
✉marion@chargesyndrome.org
http://www.chargesyndrome.org
1,2,3,6,8

CHEDIAK HIGASHI SYNDROME

See: *Hermansky-Pudlak Syndrome*

CHEMKE SYNDROME

See: *Hydrocephalus; Lissencephaly*

CHIARI MALFORMATION

See: *Arnold-Chiari Malformation*

CHILD SYNDROME

See: *Ichthyosis*

CHOLESTATIS WITH PERIPHERAL PULMONARY STENOSIS

See: *Alagille Syndrome*

CHOLESTERYL ESTER STORAGE DISEASE

See: *Tay-Sachs Disease*

CHONDRODYSPLASIA PUNCTATA

See: *Growth Disorders; Ichthyosis*

CHORIONIC VILLUS SAMPLING, RELATED DISABILITIES

See also: Limb Disorders

CVS Parent Network Support Group
15706 Reynolds Ln.
Oak Forest, IL 60452
(815) 462-0708
✉midsun@aol.com
1,2,3,4,7,9

CHOROIDEREMIA

See: *Macular Diseases; Retinitis Pigmentosa; Visual Impairments*

CHRIST-SIEMENS-TOURAINE SYNDROME

See: *Craniofacial Disorders; Ectodermal Dysplasias*

CHROMOSOME 13 & 18 DISORDERS

See also: Chromosome 18 Disorders

SOFT: Support Organization for Trisomy 18, 13 and Related Disorders
2982 S. Union St.
Rochester, NY 14624
(800) 716-7638
(716) 594-1957 (fax)
✉barbsoft@aol.com
http://www.trisomy.org
1,2,3,5,6,9; *also covers other rare trisomy disorders*

CHROMOSOME 4P-

See also: Wolf-Hirschorn Syndrome

Chromosome 4P- Support Group
Sharon York
2585 Taylor
Longview, WA 98632
(360) 577-9033
✉syork@scattercreek.com

Priority 4 Families Support Group (WHS & 4p-)
c/o Brenda Grimmett
5536 Virginia Ct.
Amherst, OH 44001
(440) 282-1460 (Phone)
(440) 989-2005 (fax)
✉bgrimmett@eriecoast.com
http://priority4familes.tripod.com
1,2,3,6,9 ; Covers all Chromosome 4 abnormalities

CHROMOSOME 5P-
See: *Cri Du Chat Syndrome*

CHROMOSOME 8P DISORDERS

8p Duplication Support Group
Genetics Ctr.
Children's Medical Ctr.
1 Children's Plaza
Dayton, OH 45404
(937) 641-5645
(937) 641-5325 (fax)
✉genemail@aol.com
3,4,9

CHROMOSOME 9 DISORDERS

Chromosome 9p-Network
675 N. Round Table Dr.
Las Vegas, NV 89110
(702) 453-0788
(702) 459-4711 (fax)
✉beverly.udell@9pminus.org
http://www.9pminus.org
1,2,3,6,8,9

Trisomy 9 International Parent Support
Children's Hospital of Michigan
3901 Beaubien Blvd.
Detroit, MI 48201-2196
(313) 745-4513
(313) 745-4827 (fax)
2,3

CHROMOSOME 17P-
See: *Smith-Magenis Syndrome*

CHROMOSOME 11Q-

Chromosome 11Q- Research and Resource Group
University of Colorado
Campus Box 295
Boulder, CO 80309
✉biasca@colorado.edu
http://ucsu.colorado.edu/~bia

CHROMOSOME 18 DISORDERS
Chromosome 18 Registry &
Research Society
6302 Fox Head
San Antonio, TX 78247
(210) 657-4968 (voice/fax)
✉office@chromosome18.org
http://chromosome18.org
1,2,3,4,6,9

CHROMOSOME 21 RING
See: *Chromosome Deletions*

CHROMOSOME 22 RING
See also: Chromosome Deletions

Chromosome 22 Central
259 Kent Ave.
Timmins, ON CAN P4N 3C2
(705) 268-3099 (voice/fax)
✉98152@c22c.org
http://www.c22c.org
1,2,3,9; *Covers all Chromosome 22-related disorders.*

CHROMOSOME 3, MONOSOMY 3P2
See: *Chromosome Deletions*

CHROMOSOME 4 RING
See; *Chromosome Deletions; Wolf-Hirschhorn Syndrome*

CHROMOSOME 45,X
See: *Turner Syndrome*

CHROMOSOME 45,X/46,XX
See: *Turner Syndrome*

CHROMOSOME 46XY/47,XXY
See: *Klinefelter Syndrome*

CHROMOSOME 47,XXY
See: *Klinefelter Syndrome*

CHROMOSOME 47,XYY
See: *Klinefelter Syndrome*

CHROMOSOME 48,XXXY
See: *Klinefelter Syndrome*

CHROMOSOME 48,XXYY
See: *Klinefelter Syndrome*

CHROMOSOME 49,XXXXY
See: *Klinefelter Syndrome*

CHROMOSOME 9 RING
See: *Chromosome Deletions; Craniofacial Disorders*

CHROMOSOME DELETIONS

Chromosome Deletion Outreach, Inc.
Box 724
Boca Raton, FL 33429-0724
(888) 236-6880
(561) 391-5098
(561) 395-4252 (fax)
✉cdo@att.net
http://www.chromodisorder.org
1,2,4,9; *Also deals with chromosome translocations, inversions, Rings trisomies*

CHROMOSOME DISORDERS
See also: Chromosome 13 & 18 Disorders

Chromosome 22 Central
237 Kent Ave.
Timmins, ON CAN P4N 3C2
(705) 268-3099 (voice/fax)
✉9815@czzc.org
http://www.czzc.org.
1,2,3,9

CHROMOSOME INVERSIONS

National Center on Chromosome Inversions
1029 Johnson St.
Des Moines, IA 50315
(515) 287-6798 (voice/fax)
✉Jackie/Barker@hotmail.com
http://www.Barkersnet.com/NC
FCI
3,9

CHROMOSOME TRANSLOCATIONS
See: *Chromosome Deletions*

CHROMOSOME TRISOMY DISORDERS
See: *Chromosome 13 & 18 Disorders*

CHRONIC ENCEPHALITIS & EPILEPSY
See: *Rasmussen Syndrome*

CHRONIC FATIGUE SYNDROME

CFIDS Association of America Youth Alliance
PO Box 220398
Charlotte, NC 28222-0398
(800) 442-3437
(704) 365-9755 (fax)
✉info@cfids.org
http://www.cfids.org
1,2,4,6,7,8

CHRONIC INFLAMMATORY DEMYELINATING POLYNEUROPATHY
See: *Autoimmune Disorders*

CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY
See: *Guillain-Barré Syndrome*

CHRONIC LOCALIZED ENCEPHALITIS
See: *Rasmussen Syndrome*

CITRULLINEMIA
See: *Urea Cycle Disorders*

CLEFT PALATE
See also: Craniofacial Disorders

Cleft Palate Foundation
104 Estes Dr., Ste. 204
Chapel Hill, NC 27514
(800) 242-5338
(919) 933-9044
(919) 933-9604 (fax)
✉cleftline@aol.com
http://www.cleftline.org
7,8; *Spanish materials*

CMV, CONGENITAL
See: *Cytomegalovirus (CMV), Congenital*

COBALAMIN (B12) DEFIENCY
See also: Metabolic Disorders

Cobalamin Network
PO Box 174
Thetford Center, VT 05075-0174
(802) 785-4029
✉suebee18@valley.net
3

COCKAYNE SYNDROME
See also: Growth Disorders; Xeroderma Pigmentosum

Share and Care Cockayne Syndrome Network
c/o Shirley Rodriguez
PO Box 570618
Dallas, TX 75357
(972) 613-6273
(972) 613-4590 (fax)
✉J93082@Aol.com
1,2,3,4,6,8,9; *Spanish and Japanese materials*

COFFIN-SIRIS' SYNDROME
See: *Ectodermal Dysplasias*

COFFIN-LOWRY SYNDROME

Coffin-Lowry Syndrome Foundation
c/o Mary C. Hoffman
3045 255th Ave. SE
Sammamish, WA 98075
(425) 427-0939
✉clsfoundation@yahoo.com
http://www.clsfoundation.tripod
.com
1,2,3,9

COGAN'S SYNDROME
See: *Autoimmune Disorders*

COLITIS
See: *Crohn Disease & Colitis*

COLOBOMA
See: *Visual Impairments*

COLON CANCER, HEREDITARY

Hereditary Colon Cancer Registry
c/o Jill D. Brensinger
Johns Hopkins Hospital
550 N. Broadway, Ste. 108
Baltimore, MD 21205
(410) 614-4038
(410) 614-9544 (fax)
✉hccregistry@jhmi.edu
http://www.hopkins-
coloncer.org
3,9

Hereditary Colon Cancer Association (HCCA)
3601 N. 4th Avenue Suite 201
Sioux Falls, SD 57104−0787
(800) 264-6783
(605) 373-2067
(605) 336-6699 (FAX)
✉hcca99@mcledusa.net
lhttp://www.hereditarycc.org
1,2,3,4,6,7.8.9; *Also provides supports for attenuated adematous polyposis coli, familial adenomatous polyposis, familial juvenile polyposis, Gardner syndrome, hereditary nonpolyposis colorectal cancer, Peutz-Jegher syndrome, and Turcot syndrome.*

COMPLEX REGIONAL PAIN SYNDROME
See: *Reflex Sympathetic Dystrophy Syndrome*

CONGENITAL ADRENAL HYPERPLASIA (CAH)
See also: Adrenal Disorders

CARES Foundation Inc
PO Box 264
Short Hills, NJ 07078-0264
(866) 227-3737
(973) 912-3895
(973) 912-3894
✉kelly@caresfoundation.org
http://www.caresfoundation.
org
1,2,3,4,7,8

CONGENITAL LIPOID HYPERPLASIA
See: *Adrenal Disorders*

CONGENITAL SENSORY NEUROPATHY WITH ANHIDROSIS
See: *Familial Dysautonomia*

KEY TO SERVICES
1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

CONNECTIVE TISSUE DISORDERS
See also: Ehlers-Danlos Syndrome; Epidermolysis Bullosa, Dystrophic; Marfan Syndrome; Pseudoxanthoma Elasticum (PXE)

Coalition for Heritable Disorders of Connective Tissue
382 Main St.
Port Washington, NY 11050
(800) 862-7326
(516) 883-8712
(516) 883-8040 (fax)
✉staff@marfan.org
http://www.marfan.org
2,7

CONRADI-HÜNERMANN SYNDROME
See: *Growth Disorders; Ichthyosis*

COOLEY ANEMIA/ THALASSEMIA MAJOR
See also: Autoimmune Disorders

Cooley's Anemia Foundation
129-09 26th Ave., Ste. 203
Flushing, NY 11354
(800) 522-7222
(718) 321-2873
(718) 321-3340 (fax)
✉info@cooleysanemia.org
http://www.cooleysanemia.org
1,2,3,4,5,6,7,8,9; *Chinese, Italian, Korean, Vietnamese materials available in limited quantity*

Thalassemia Action Group
12909 26th Ave., Ste. 203
Flushing, NY 11354
(800) 522-7222
(718) 321-2873
(718) 321-3340 (fax)
✉ncaf@aol.com
1,2,3,4,5,6,7,8,9

Thalassemia Foundation
32 Fern Ave.
Weston, ON CAN M9N 1M2
(416) 242-8425
✉josie.sirna@utoronto.ca
1,2,3,4,5,6,8,9

COPPER DEFICIENCY, X-LINKED
See: *Menkes Disease*

COPPER MALABSORPTION, X-LINKED
See: *Menkes Disease*

CORI DISEASE
See: *Glycogen Storage Diseases, Muscular Dystrophy*

CORNELIA DE LANGE SYNDROME

Cornelia de Lange Syndrome Foundation
302 W. Main St. #100
Avon, CT 06001-3681
(800) 223-8355
(860) 676-8166
(860) 676-8337 (fax)
✉cdlsintl@iconn.net
http://cdlsoutreach.org
1,2,3,4,6

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

CORPUS CALLOSUM DISORDERS

See: *Agenesis of the Corpus Callosum; Aicardi Syndrome*

COX DEFICIENCY

See: *Mitochondrial Disorders*

CRANIOCARPOTARSAL DYSTROPHY

See: *Freeman-Sheldon Syndrome*

CRANIOECTODERMAL SYNDROME

See: *Ectodermal Dysplasias*

CRANIOFACIAL DISORDERS

See also: Apert Syndrome; Blepharophimosis, Ptosis, Epicanthus Inversus Syndrome Carpenter Syndrome (BPES); Chromosome11q; Cleft Palate; Dubowitz Syndrome, Freeman-Sheldon Syndrome; Goldenhar Syndrome; Holoprosencephaly; Microtia; Moebius Syndrome; Nager & Miller Syndromes; Nevi, Giant Congenital; Robinow Syndrome; Rubinstein-Taybi Syndrome; Sturge-Weber Syndrome; Treacher Collins Syndrome; Velo Cardio-Facial Syndrome

AboutFace International
123 Edwards St. Ste 1003
Toronto, ON CAN M5G1E2
(800) 665-3223
(416) 597-2229
(416) 547-8494 (fax)
✉abtface@interlog.com
http://www.interlog.com/abtface
1,2,3,4,5,6,7

AboutFace USA
1407-1/2 N. wells
Chicago, IL 60610
(888) 486-1209
✉AboutFace2000@aol.com
http://www.aboutface2000.org
1,2,3,4,5,6,7

Tennessee Craniofacial Center
c/o Terri Farmer
975 E. Third St.
Chattanooga, TN 37403
(800) 418-3223
(423) 778-9192
(423) 778-8172 (fax)
✉dnkm90@prodigy.com
http://www.erlanger.org/cranio
1,2,3,5,7

Craniosynostosis and Positional Plagioceoha,ly Support, Inc. (CAPPS)
2965-A Quarters
Quantuco, VA 22134
(877) 686-CAPS (2277)
(866) 454-5902
(703) 445-1078 (fax)
✉stpnjep@aol.com
http://caps2000.org

FACES–The National Craniofacial Association
PO Box 11082
Chattanooga, TN 37401
(800) 3FACES3 (332-2373)
(423) 266-1632
(423) 267-3124 (fax)
✉faces@faces-cranio.org
http://www.faces-cranio.org
1,2,3,4,7,9; *financial assistance for medical-related travel*

Forward Face: The Charity for Children with Craniofacial Conditions
Inst. of Reconstructive Plastic Surgery
317 E 34th St., Suite 901A
New York, NY 10016
(800) 393-3223
(212) 684-5860
(212) 684-5864 (fax)
1,2,3,4,5,6,7,8,9

Let's Face It
PO Box 29972
Bellingham, WA 98228-1972
(360) 676-7325
✉letsfaceit@faceit.org
http://www.faceit.org
1,2; *Publishes biannual resource guide*

National Foundation for Facial Reconstruction
317 E. 34th St., Rm. 901
New York, NY 10016
(212) 263-6656
(212) 263-7534 (fax)
✉info@nffr.org
http://www.nffr.org
2,3,4,8,9

Children's Craniofacial Association
Charlene Smith
Executive Director
12200 Park Central Dr., Ste 180
Dallas, TX 75251
(800) 535-3643
(972) 566-5980
(972) 566-8489(fax)
✉contactCCA@ccakids.com
http://www.ccakids.com
1,2,3,4,6; *Spanish materials; Financial assistance for related expenses; Annual family retreat*

CRANIOSYNOSTOSIS

See: *Craniofacial Disorders*

CRI DU CHAT SYNDROME

5p- Society
PO Box 268
Lakewood CA 90914-0268
(888) 970-0777
(714) 901-1544
(562) 920-5240 (fax)
✉director@fivepminus.org
http://www.fivepminus.org
1,2,3,6,7,9

CRIB DEATH

See: *Sudden Infant Death Syndrome (SIDS)*

CRIGLER-NAJJAR

See: *Liver Disease and Transplant*

CROHN DISEASE & COLITIS

CCFA: Crohn's & Colitis Foundation of America
386 Park Ave. S., 17th Fl.
New York, NY 10016-8804
(800) 932-2423
(212) 685-3440
(212) 779-4098 (fax)
✉info@ccfa.org
http://www.ccfa.org
1,2,3,4,5,6,7,8.,9

Crohn's and Colitis Foundation of Canada
301-21 St. Clair Ave. E.,
Toronto, ON CAN M4T 1L9
(800) 387-1479 (Canada only)
(416) 920-5035
(416) 929-0364 (fax)
✉ccfc@ccfc.ca
http://www.ccfc.ca
1,2,5,6,8,9; *French materials*

Pediatric Crohn's & Colitis Association
PO Box 188
Newton, MA 02168
(617) 489-5854 (voice/fax)
1,2,3,4,7,8

CROUZON DISEASE

See: *Craniofacial Disorders*

CURLY HAIR-ANKYLOBLEPHARON-NAIL DYSPLASIA (CHANDS)

See: *Ectodermal Dysplasias*

CUSHING SYNDROME

See: *Adrenal Disorders*

CUTIS HYPERELASTICA

See: *Ehlers-Danlos Syndrome*

CUTIS LAXA

See: *Connective Tissue Disorders*

CYCLIC VOMITING SYNDROME

Cyclic Vomiting Syndrome Association
3585 Cedar Hill Rd. NW
Canal Winchester, OH 43110
(614) 837-2586 (phone/fax)
✉waitesd@cvsaonline.org
http://www.cvsaonline.org
1,2,3,4,5,6,8,9

CYSTIC FIBROSIS

Canadian Cystic Fibrosis Foundation
2221 Yonge St., Ste. 601
Toronto, ON CAN M4S 2B4
(800) 378-2233 (Canada only)
(416) 485-9149
(416) 485-0960 (fax)
✉info@cysticfibrosis,ca
http://www.cysticfibrosis.ca
1,2,4.5,6,7,8.9; *English & French brochures and booklets; Videos available in French and English.*

Cystic Fibrosis Foundation
6931 Arlington Rd., 2nd Fl.
Bethesda, MD 20814
(800) FIGHT CF (344-4823)
(301) 951-4422
(301) 951-6378 (fax)
✉info@cff.org
http://www.cff.org
1,2,4,5,6,7,8,9

CYSTINOSIS

See also: Kidney Disorders

Cystinosis Foundation
2516 Stockbridge Dr.
Oakland, CA 94611
(800) 392-8458
(209) 222-7997
✉jd2jptz@qmis.net
http://www.cystinosis.com
1,2,3,6,7,8; *Italian and French materials.*

CYSTINURIA

See also: Kidney Disorders

Cystinuria Support Network
21001 NE 36th St.
Sammamish, WA 98074
(425) 868-2996
(425) 897-0675 (fax)
✉cystinuria@aol.com
http://www.cystinuria.com
1,3

CYTOCHROME C OXIDASE (COX) DEFICIENCY

See: *Lactic Acidosis, Mitochondrial Disorders*

CYTOMEGALOVIRUS (CMV), CONGENITAL

Clinical Care Center
CMV Registry, Feigin Ctr.
Ste. 1150
1102 Bates St.
Houston, TX 77030-2399
(832) 824-4387
(832) 825-4347 (fax)
✉cmv@bcm.tmc.edu
http://www.bcm.tmc.edu/pedi/infect/cmv.
1,2,3,4

DANDY-WALKER SYNDROME

See also: Hydrocephalus

Dandy Walker Syndrome Network
5030 142nd Path W.
Apple Valley, MN 55124
(952) 423-4008
2,3,4

DARIER DISEASE

See: *Ichthyosis*

DE BARSEY SYNDROME

See: *Connective Tissue Disorders*

DE BARSEY-MOENS-DIERCKS SYNDROME

See: *Connective Tissue Disorders*

DE MORSIER SYNDROME

See: *Septo-Optic Dysplasia*

DEAF-BLIND

See also: Hearing Impairments; Visual Impairments

American Association of the Deaf-Blind
814 Thayer Ave., Ste. 302
Silver Spring, MD 20910
(800) 735-2258 (Voice)
(301) 588-6545 (TDD)
(301) 588-8705 (fax)
1,2,6,7

National Family Association for Deaf-Blind
111 Middle Neck Rd.
Sands Point, NY 11050-1129
(800) 255-0411, ext.275
(516) 944-8637 (TDD)
(516) 944-7302 (fax)
✉nfadb@aol.com
http://www.NFAD.org
1,2,3,4,6,7; *Newsletter available by request in braille, on disk (WP5.1) or large print.*

The Canadian Deafblind and Rubella Association
c/o The W. Ross Macdonald School
350 Brant Ave.
Brantford, ON CAN N3T 3J9
(519) 754-0729
(519) 754-5400 (fax)
1,2,7

DEAFNESS

See: *Hearing Impairments*

DEBRANCHER ENZYME DEFICIENCY

See: *Glycogen Storage Diseases; Muscular Dystrophy*

DECARBOXYLICACIDURIA

See: *Fatty Oxidation Disorder*

DECEREBRATE DEMENTIA

See: *Subacute Sclerosing Panencephalitis*

DEJERINE SOTTAS DISEASE

See: *Muscular Dystrophy*

DEJERINE-LANDOUZY

See: *Muscular Dystrophy; Facio-Scapulo-Humeral Muscular Dystrophy*

DELTA STORAGE POOL DISEASE

See: *Hermansky-Pudlak Syndrome*

DENTOOCULOCUTANEOUS SYNDROME

See: *Ectodermal Dysplasias*

DERMATITIS HERPETIFORMIS

See: *Celiac Disease; Celiac Sprue; Gluten Intolerance*

DERMATOCHALASIA

See: *Connective Tissue Disorders*

DERMATOLYSIS

See: *Connective Tissue Disorders*

DERMATOMEGALY

See: *Connective Tissue Disorders*

DERMATOMYOSITIS

See: *Arthritis; Muscular Dystrophy; Myositis*

DERMOODONTODYSPLASIA

See: *Ectodermal Dysplasias*

DERMOTRICHIC SYNDROME

See: *Ectodermal Dysplasias*

DEVELOPMENTAL DISABILITIES

See: *Mental Retardation*

DIABETES INSPIDUS

See also: Autoimmune Disorders

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

The Diabetes Insipidus Foundation Inc.
4533 Ridge Dr
Baltimore, MD 21229
(410) 247-3953
(610) 326-7955 (parent support)
✉diabetesinsipidus@maxinter.
net
http://diabetesinsipidus.
maxinter.net
1,2,3,4

DIABETES MELLITUS

See also: Autoimmune Disorders, Kidney Disorders

American Diabetes Association
Government Relations
Department
1701 N. Beauregard Street
Alexandria, VA 22311
(703) 549-1500
(703) 549-8748(fax)
http://www.diabetes.org
1,2,4,5,6,7,8

Canadian Diabetes Association
15 Toronto St., Ste. 800
Toronto, ON CAN M5C 2E3
(416) 363-3373
(416) 363-3393 (fax)
✉info@diabetes.ca
http://www.diabetes.ca
1,2,4,5,6,7,8; *French Materials*

DIGESTIVE DISORDERS

See: Celiac Disease, Celiac Sprue, Crohn Disease & Colitis; Gluten Intolerance; Intestinal Pseudo Obstruction Syndrome; Ostomy

DIGESTIVE DYSMOTILITY

See: Intestinal Pseudo-Obstruction Syndrome

DIMORSIER SYNDROME

See: Growth Disorders

DISCOID LUPUS

See: Autoimmune Disorders

DOWN SYNDROME

Association for Children with Down Syndrome
4 Fem PL.
Plainview, NY 11803
(516) 933-4700
(516) 933-7524(fax)
✉info@acds.org
http://www.acds.org
1,2,3,4; *bilingual services*

Canadian Down Syndrome Society
811 14th St. NW
Calgary, AB CAN T2N 2A4
(800) 883-5608 (Canada only)
(403) 270-8500
(403) 270-8291 (fax)
✉dsinfo@cdss.ca
http://www.cdss.ca
1,2,3,4,5,6,7; *French materials*

Foundation for Children with Down Syndrome
3920 Blaisdell Ave. S., Ste. 1
Minneapolis, MN. 55409
(918) 836-8698
(612) 822-1032 (fax)
http://www.ffcwds.org

La Foundacion John Langdon Down, A.C.
Selva 4
Insurgentes Cuicuilco
Delegacion Coyocan, 04530
Mexico DF
(52) 66-66-8580
(52) 56-06-3800 (FAX)
✉fjldown@mail.internet.com.
mx

International Foundation for Genetic Research
500A Garden City Dr.
Pittsburgh, PA 15146
(412) 823-6380
(412) 373-7713 (fax)
✉tmf@pennet.com
http://www.pennet.com/
chuckdet/index.html
1,2,4,7,8

National Down Syndrome Congress
7000 Peachtree
Dunwoody Rd., Bldg. 5,
Ste. 100
Atlanta, GA 30328-1655
(800) 232-6372
(770) 604-9500
(770) 604-9898 (fax)
✉ndsccenter@aol.com
http://www.ndsccenter.org
1,2,4,5,6,7

National Down Syndrome Society
666 Broadway, 8th Fl.
New York, NY 10012-2317
(800) 221-4602
(212) 460-9330
(212) 979-2873 (fax)
✉info@ndss.org
http://www.ndss.org
1,2,3,4,5,6,7,8

Trisomy 21 Research Foundation
933 First Colonial Rd., Ste. 109
Virginia Beach, VA 23454
(757) 425-1969
(757) 425-1822 (fax)
✉lleichtman@macs.net
http://www.tri21.org
2,7,8,9

DUAL SENSORY IMPAIRMENTS

See: Deaf-Blind

DUBOWITZ SYNDROME

See also: Craniofacial Disorders; Growth Disorders

Dubowitz Syndrome Parent Support Network
PO Box 2441
Vincennes, IN 47591
(812) 886-0575
(812) 886-1128 (fax)
✉bobbie@dubowitz.org
http://dubowitz.org

DUCHENNE MUSCULAR DYSTROPHY

See: Muscular Dystrophy

DWARFISM

See also: Growth Disorders; Short Stature

Billy Barty Foundation
929 W. Olive Ave., Ste. C
Burbank, CA 91506
(818) 953-5410
http://www.rth.org/bbf/

Metatropic Dwarf Registry
3393 Geneva Drive
Santa Clara, CA 95051
(408) 244-6354
(408) 296-6317 (fax)
✉figone@netgate.net
http://www.u2.netgate.net/~cfi
gone/mdr/Index.htm
2,3; *physician referrals; international membership*

DYGENESIS OF THE CORPUS CALLOSUM

See: Agenesis of the Corpus Callosum

DYSAUTONOMIA

See also: Famial Dysautonomia

National Dysautonomia Research Foundation (NDRF)
421 W. Fourth St., Suite 9
Red Wing, MN 55066
(651) 267-0525
(651) 267-0524 (fax)
✉ndrf@ndrf.org
http://www.ndrf.org
1,2,3,4,5,6,7,8,9

DYSAUTONOMIA, FAMILIAL

See: Familial Dysautonomia

DYSKERATOSIS, CONGENITAL

See: Ectodermal Dysplasias

DYSLEXIA

See also: Attention Deficit Disorder; Learning Disabilities

Dyslexia Research Institute
5746 Centerville Rd.
Tallahassee, FL 32309
(850) 893-2216
(850) 893-2440 (fax)
✉dri@talstar.com
http://www.dyslexia-add.org
2,3,4

The International Dyslexia Association
8600 La Salle Rd.
Chester Bldg., Ste. 382,
Baltimore, MD 21286-2044
(800) 222-3123
(410) 296-0232
(410) 321-5069 (fax)
✉info@interdys.org
http://www.interdys.org
1,2,3,4,5,6,7,8,9; *Spanish materials*

Recording for the Blind & Dyslexic
20 Roszel Rd.
Princeton, NJ 08540
(609) 452-0606,
(609) 520-7990 (fax)
2; *Extensive lending library of academic textbooks on audiocassette (all levels)*

DYSOSTOSIS, ACROFACIAL, NAGER TYPE

See: Nager & Miller Syndromes

DYSOSTOSIS, MANDIBULOFACIAL

See: Nager & Miller Syndromes; Treacher Collins Syndrome

DYSOSTOSIS, METAPHYSEAL, TYPE B IV

See: Shwachman Syndrome

DYSOSTOSIS, POSTAXIAL ACROFACIAL

See: Nager & Miller Syndromes

DYSPLASTIC ANGIECTASIA, CONGENITAL

See: Klippel-Trenaunay Syndrome

DYSTONIA

Dystonia Medical Research Foundation
One E. Wacker Dr., Ste. 2430-
Chicago, IL 60601-1905
(312) 755-0198
(312) 803-0138 (fax)
(800) 361-8061 (In Canada only)
✉jfeeley@dystonia-
foundation.org
http://www.dystonia-
foundation.org/
1,2,3,4,5,6,7,8,9

Dystonia Medical Research Foundation—Canada
116-230 Heath St. W.
Toronto, ON CAN M5P 1N8
(800) 361-8061 (Canada only)
(416) 488-6974
(416) 488-8323
✉Dystonia@dystonia-founda-
tion.org
1,2,3,5,6,8

DYSTROPHIC EPIDERMOLYSIS BULLOSA

See: Epidermolysis Bullosa, Dystrophic

EATON-LAMBERT SYNDROME

See: Muscular Dystrophy

ECTODERMAL DYSPLASIAS

Canadian Society for Ectodermal Dysplasia (Western Canada)
304 Hawkwood Blvd., NW
Calgary, AB CAN T3G 2Y5
(416) 664-6121
2,3,4

National Foundation for Ectodermal Dysplasia
410 E. Main St.
PO Box 114
Mascoutah, IL 62258-0114
(618) 566-2020
(618) 566-4718 (fax)
✉nfed1@aol.com
http://www.nfed.org
1,2,3,4,6,7,8,9

ECTRODACTYLY-ECTODERMAL DYSPLASIA-CLEFT LIP/PALATE (EEC) SYNDROME

See: Cleft Palate; Craniofacial Disorders; Ectodermal Dysplasias

EEC SYNDROME

See: Cleft Palate; Craniofacial Disorders; Ectodermal Dysplasias

EHLERS-DANLOS SYNDROME

See also: Connective Tissue Disorders; Glaucoma; Visual Impairments

Ehlers-Danlos National Foundation
6399 Wilshire Blvd.
Suite 203
Los Angeles, CA 90048
(323) 651-3038
(323) 651-1366 (fax)
✉ednfboard@aol.com
http://www.ednf.org
1,2,3,4,5,6,8

EINTEIN SYNDROME

See: Hearing Impairments; Kidney Diseases, Hereditary; Vision Impairments

ELASTORRHEXIS

See: Connective Tissue Disorders

ELASTOSIS DYSTROPHICA SYNDROME

See: Pseudoxanthoma Elasticum (PXE)

ELEPHANTITIS

See: Lymphedema

ELLIS-VAN CREVELD SYNDROME

See: Ectodermal Dysplasias

EMERY-DREIFUSS MUSCULAR DYSTROPHY

See: Muscular Dystrophy

EMG SYNDROME

See: Beckwith-Wiedemann Syndrome

ENCEPHALITIS, CHRONIC LOCALIZED

See: Rasmussen Syndrome

ENCEPHALITIS & EPILEPSY, CHRONIC

See: Rasmussen Syndrome

ENCEPHALITIS, RASMUSSEN

See: Rasmussen Syndrome

ENCEPHALOFACIAL ANGIOMATOSIS

See: Sturge-Weber Syndrome

ENCEPHALOMYELOPATHY

See: Lactic Acidosis; Mitochondrial Disorders

ENCEPHALOMYELORADICULOPATHY, ACUTE ISSEMINATED

See: Guillain-Barré Syndrome

ENCEPHALOTRIGEMINAL ANGIOMATOSIS

See: Sturge-Weber Syndrome

ENCHONDROMATOSIS, ENCHONDROSES

See: Ollier Disease

ENDOCARDIAL FIBROSLASTOSIS

See: Heart Disorders

ENTEROPATHY, GLUTEN-SENSITIVE

See: Celiac Disease; Celiac Sprue; Gluten Intolerance

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

EOSINOPHILIC GRANULOMA
See: *Histiocytosis*

EPICANTHUS INVERSUS
See: *Blepharophimosis, Ptosis, Epicanthus Inversus Syndrome (BPES)*

EPIDERMOLYSIS BULLOSA, DYSTROPHIC
See also: *Connective Tissue Disorders*

DEBRA: Dystrophic Epidermolysis Bullosa Research Association
40 Rector St., Ste. 1403
New York, NY 10006
(212) 513-4090
(212) 513-4099 (fax)
✉staff.debra@exario.net
http://www.debra.org
1,2,3,4,5,6,7,8,9, *Spanish materials*

EPIDERMOLYTIC HYPERKERATOSIS
See: *Ichthyosis*

EPILEPSY
See also: *Seizure Disorders*

American Epilepsy Society
842 North Main St.
West Hartford, CT 06117-2507
(860) 586-7505
(860) 586-7550 (fax)
✉info@aesnet.org
http://www.aesnet.org
2,8

Epilepsy Canada
1470 Peel St., Ste. 745
Montreal, QUE CAN H3A 1T1
(877) SEIZURE (734-0873)
(514) 845-7855
(514) 845-7866 (fax)
✉epilepsy@epilepsy.ca
http://www.epilepsy.ca
1,2,4,5,6,7,8; *French materials*

Epilepsy Foundation of America
4351 Garden City Dr.
Landover, MD 20785-2267
(800) 332-4050
(301) 459-3700
(301) 577-2684 (fax)
✉postmaster@efa.org
http://www.efa.org
1,2,4,5,6,7; *Spanish materials*

EPILOIA
See: *Tuberous Sclerosis*

ERB PALSY

Brachial Plexus/Erb's Palsy Support and Informational Network, Inc.
PO Box 23
Larsen, WI 54947
(920) 836-9587
http://www.customforum.com/nationalbpi
✉nationalbpi@poweronline.com
1,2,3,4,5,6

ERB/DUCHENNE PALSY
See: *Erb Palsy*

ERDHEIM-CHESTER DISEASE
See: *Histiocytosis*

ERYTHROBLASTOPHTHISIS
See: *Anemia, Aplastic*

ERYTHROBLASTOTIC ANEMIA OF CHILDHOOD
See: *Cooley Anemia*

ERYTHROID HYPOPLASIA, CONSTITUTIONAL
See: *Anemia, Diamond-Blackfan*

ERYTHROHEPATIC PROTOPORPHYRIA
See: *Liver Disorders; Porphyria*

ERYTHROKERATODERMIAS
See: *Ichthyosis*

ERYTHROPHAGOCYTIC LYMPHOHISTIOCYTOSIS, FAMILIAL
See: *Histiocytosis*

ESOPHAGEAL ATRESIA
See: *VACTERL Association*

EVANS SYNDROME
See also: *Autoimmune Disorders; Neutropenia*

Evans Syndrome Support and Research Group
c/o Lou Addington
5630 Devon St.
Port Orange, FL 32127
(904) 760-3031
(904) 760-5583 (fax)
73142.1315@compuserve.com
3,4,9

EXOMPHALOS-MACROGLOSSIA-GIGANTISM (EMG) SYNDROME
See: *Beckwith-Wiedemann Syndrome*

EXOSTOSES, MULTIPLE HEREDITARY

The MHE Coalition/
MHE Family Support Group
Chele Zelina
8838 Holly Lane
Olmsted Falls, OH 44138
(440) 235-6325 or
(440) 427-9032
✉CheleZ1@aol.com
http://www.radix.net/~hogue/mhe.htm
1,2,3,4,9; upcoming conference at the University of Arizona, Spring 2002

MHE and Me—A Support Group for Kids With Multiple Hereditary Exostoses and Their Families
14 Stony Brook Dr.
Pine Island, NY 10969
(845) 258-6058
✉mheandme@yahoo.com
http://www.geocities.com/mheandme
2,3; *Some info. in Spanish*

EXTRACORPOREAL MEMBRANE OXYGENATION

ECMO Moms and Dads International Parent Support
PO Box 53848
Lubbock, TX 79453
(806) 892-3348
(806) 792-1289 (fax)
✉bgw@odsy.net
2,3,

FABRY DISEASE
See also: *Tay-Sachs Disease*

International Center for Fabry Disease
Dept. of Human Genetics
Mt. Sinai School of Medicine
5th Ave. at 100th St.
Box 1498
New York, NY 10029
(866) 322-7963 (for parents)
(212) 659-6700
(212) 360-1809 (fax)
✉fabry.disease@mssm.edu
http://www.mssm.edu/crc/Fabry
1,2,3,7,9

FACIAL DISFIGUREMENT
See: *Craniofacial Disorders*

FACIAL PARALYSIS
See: *Bell's Palsy*

FACIO-AURICULO-VERTEBRAL ANOMALY
See: *Goldenhar Syndrome*

FACIO-CARDIO-CUTANEOUS SYNDROME
See: *Heart Disorders; Ichthyosis*

FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY

FSH Society, Inc.
3 Westwood Rd.
Lexington, MA 02420
(781) 860-0501
(781) 860-0599 (fax)
✉carol.perez@fshsociety.org
http://www.fshsociety.org
1,2,3,4,5,6,7,8,9

FAMILIAL ATAXIA
See: *Ataxia; Friedreich Ataxia*

FAMILIAL ADENOMATOUS POLYPOSIS
See: Colon Cancer, Hereditary

FAMILIAL DYSAUTONOMIA
See also: *Dysautonomia*

FD Familial Dysautonomia Foundation
343 Clarke Ave. W., Ste. 1103
Thornhill, ON CAN L4J 7K5
(905) 882-7725
(905) 764-7752 (fax)
1,2,3,4,5,6,8,9

Dysautonomia Foundation
633 3rd Ave., 12th Fl.
New York, NY10017
(212) 949-6644
(212) 682-7625 (fax)
1,2,8

FAMILIAL JUVENILE POLYPOSIS
See: Colon Cancer, Hereditary

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

FAMILIAL PEMPHIGUS
See: *Ichthyosis*

FAMILIAL SPLENIC ANEMIA
See: *Gaucher Disease*

FANCONI ANEMIA
See: *Anemia, Fanconi*

FANCONI II
See: *Cystinosis*

FANCONI PANMYELOPATHY
See: *Anemia, Fanconi*

FARBER DISEASE
See: *Tay-Sachs Disease*

FAS/FAE
See: *Fetal Alcohol Syndrome/Effect*

FATTY OXIDATION DISORDER
See also: *Metabolic Disorders*

FOD Family Support Group
805 Montrose Dr.
Greensboro, NC 27410
(336) 547-8682
✉fodgroup@aol.com
http://www.fodsupport.org
1,2,3,7

FEMALE SEX CHROMOSOME DISORDERS
See: *Turner Syndrome*

FETAL ALCOHOL SYNDROME/EFFECT

Council on Alcoholism & Drug Abuse of Bergen, Inc.
10 E. Broadway
Hackensack, NJ 07601
(201) 488-8680
(201) 488-8724 (fax)
2,3,4

Family Empowerment Network: Supporting Families Affected by FAS/FAE
517 Lowell Center
610 Langdon St.
Madison, WI 53703
(800) 462-5254
(608) 262-6590
(608) 265-3352 (fax)
✉fen@dcs.wisc.edu
1,2,3,4,6,7; *Spanish materials*

Fetal Alcohol Education Program
1975 Main St.
Concord, MA 01742
(508) 369-7713
2,3,4,9

National Organization on Fetal Alcohol Syndrome
216 G. St., NE
Washington, DC 20002
(800) 66 NOFAS (66327)
(info. line)
(202) 785-4585
(202) 466-6456 (fax)
✉nofas@erols.com
http://www.nofas.org
1,2,3,4; *available in English and Spanish*

The Fetal Alcohol Syndrome Family Resource Institute
PO Box 2525
Lynnwood, WA 98036
(800) 999-3429
(253) 531-2878
(253) 531-2668 (fax)
✉vicfas@hotmail.com
http://www.fetalalcoholsyndrome.org
1,2,3,4,5,6,9

Fetal Alcohol Support Network
2266 Homeland Dr.
Mississauga, ON CAN L5K 1G6
(905) 822-0733 (voice/fax)
1,2,3,4,9

FETAL FACE SYNDROME
See: *Robinow Syndrome*

FETAL IRITIS SYNDROME
See: *Norrie Disease*

FG SYNDROME
See also: *Opitz Syndrome*

FG Syndrome Family Alliance, Inc.
3839 NW Eastview Pl.
Corvallis, OR 97330
(541) 753-8075
http://www.fg-syndrome.org

FIBROMYALGIA
See: *Arthritis*

FIBRODYSPLASIA OSSIFICANS PROGRESSIVA

International Fibrodysplasia Ossificans Progressiva Association
PO Box 196217
Winter Springs FL 32719-6217
(407) 365-4194
(407) 365-3213 (Fax)
1,2,3,8

FIBROUS DYSPLASIA, MONOSTOTIC
See: *McCune-Albright Syndrome*

FIRST AND SECOND BRANCHIAL ARCH SYNDROME
See: *Goldenhar Syndrome*

FISCHER SYNDROME
See: *Guillain-Barré Syndrome*

FISCHER-JACOBSEN-CLOUSTON SYNDROME
See: *Ectodermal Dysplasias*

FOCAL DERMAL HYPOPLASIA (FDH) SYNDROME
See: *Craniofacial Disorders; Ectodermal Dysplasias; Hearing Impairments*

FOLATE METABOLISM; INBORN ERROR OF
See: *Cobalamin (B12) Defiency*

FOOD ALLERGY

See also: Asthma & Allergy

The Food Allergy and Anaphylaxis Network
10400 Eaton Pl., Ste. 107
Fairfax, VA 22030-2208
(800) 929-4040
(703) 691-2713 (fax)
✉faan@foodallergy.org
http://www.foodallergy.org
1,2,6,7,9

FORBES DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy

FRAGILE X SYNDROME

See also: Attention Deficit Disorder; Autism; Learning Disabilities

FRAXA Research Foundation
45 Pleasant St.
Newburyport, MA 01950
(978) 462-1866
(978) 463-9985 (fax)
✉info@fraxa.org
http://www.fraxa.org
1,2,3,5,7,8,9; *Internet mailing list*

National Fragile X Foundation
PO Box 190488
San Francisco, CA 94119-0488
(800) 688-8765
(510) 763-6223 (fax)
✉NATLFX@sprintmail.com
http://www.FragileX.org
1,2,3,4,5,6,7,8

FRANCHESCHETTI-KLEIN SYNDROME

See: Treacher Collins Syndrome

FRAXA

See: Fragile X Syndrome

FREDREICH DISEASE

See: Ataxia; Friedreich Ataxia

FREDREICH TABES

See: Ataxia; Friedreich Ataxia

FREEMAN-SHELDON SYNDROME

See also: Craniofacial Disorders

Freeman-Sheldon Parent Support Group
509 E. Northmont Wy.
Salt Lake City, UT 84103
(801) 364-7060
✉fspsg@aol.com
http://www.fspsg.org
1,2,3,4,7,9.

FRIEDREICH ATAXIA

See also: Ataxia; Muscular Dystrophy

Canadian Association of Friedreich's Ataxia
5620 C A Jobin St.
Montreal, QUE CAN H1P 1H8
(514) 321-8684
(514) 321-9257 (fax)
http://www.cam.org/~acaf
1,2,8,9; *French materials*

FUCOSIDOSIS

See: Tay-Sachs Disease

FULLER-ALBRIGHT SYNDROME

See: McCune Albright Syndrome

FULMINATING HYPERPYREXIA

See: Malignant Hyperthermia

GALACTOSE-1-PHOSPHATE URIDYL TRANSFERASE DEFICIENCY

See: Galactosemia

GALACTOSEMIA

See also: Metabolic Disorders, Liver Disease

Parents of Galactosemic Children Inc.
885 Del Sol St.
Sparks, NV 89436
(775) 626-0885
http://www.galactosemia.org
1,2,5,6

GARDNER SYNDROME

See: Colon Cancer, Hereditary, Polyposis

GASTROESOPHAGEAL REFLUX

See also: Intestinal Pseudo-Obstruction Syndrome

Gastroesophageal Reflux (GER) Pediatric/Adolescent Gastroesophageal Reflux Association Inc. (PAGER)
PO Box 1153
Germantown, MD 20875-1153
(301) 601-9541
✉gergroup@aol.com
http://www.reflux.org
1,2,3,5,6,8,9

GASTROINTESTINAL CANCER

See: Colon Cancer, Hereditary, Polyposis

GASTROINTESTINAL DISORDERS

The Oley Foundation
214 Hun Memorial
Albany Medical Center, A-28
Albany, NY 12208-3478
(800) 776-OLEY (6539)
(518) 262-5079
(518) 262-5528 (fax)
✉BishopJ@mail.amc.edu
http://www.oley.org
1,2,3,4,5,6,7,9

GAUCHER DISEASE

See also: Tay-Sachs Disease

National Gaucher Foundation
11140 Rockville Pike, Ste. 350
Rockville, MD 20852-3106
(800) 925-8885
(301) 816-1515
(301) 816-1516 (fax)
✉ngf@gaucherdisease.org
http://www.gaucherdisease.org
1,2,3,4,5,6,7,8,9

GENEE-WIEDEMANN SYNDROME

See: Nager & Miller Syndromes

GENETIC DISORDERS

Genetic Alliance
4301 Connecticut Ave. NW, Ste. 404
Washington, DC 20008-2304
(202) 966-5557
(202) 966-8553 (fax)
(800) 336-GENE (4363) helpline
http://www.geneticalliance.org
✉info@geneticalliance.org
1,2,3,4,6,7,9; *Spanish materials; rare chromosome abnormalities*

Association of Genetic Support Inc. (AGSA)
66 Albion St,
Surry Hills, Australia NSW 2010
(02) 9211 1462,
(02) 9211 8077 (fax)
✉agsa@ozomail.com.au
http://www.agsa-geneticsupport.org.au
1,2,3,4; *annual genetics awareness week; counseling, information, and support*

Northeast VCFS Support Group
2 Lansing Dr.
Salem, NH 03079
(603) 898-6332
✉MLADIA@aol.com
http://www.vcfsef.org
1,2,3,4,6

GENITALIA, AMBIGUOUS

See also: Hermaphroditism

Ambiguous Genitalia Support Network (AGSN)
PO Box 313
Clements, CA 95227-0313
✉agsn@jps.net
http://www.jps.net/agsn
2,3,4,6,7

GILFORD SYNDROME

See: Progeria

GINGIVAL FIBROMATOSIS AND HYPERTRICHOSIS

See: Ectodermal Dysplasias

GIROUX-BARBEAU SYNDROME

See: Ichthyosis

GLAUCOMA

See also: Visual Impairments

Glaucoma Research Foundation
200 Pine Street Ste. 200
San Francisco, CA 94104
(800) 826-6693
(415) 986-3162
✉info@glaucoma.org
http://www.glaucoma.org
1,2

GLUCOSYL CEREBROSIDE LIPIDOSIS

See: Gaucher Disease

GLUTARIC ACIDURIA, TYPE I

See also: Acidemia, Organic; Lactic Acidosis

International Organization for Glutaric Aciduria, Type I
IOGA
Rd #4, Box 299-A
Blairsville PA 15717
(724) 459-0179
✉cswelch@helicon.net
http://www.glutaricacidemia.org
2,3,4,6,7,8

GLUTARICACIDURIA I

See: Glutaric Aciduria, Type I

GLUTARICACIDURIA II

See: Acidemia, Organic; Lactic Acidosis

GLUTEN INTOLERANCE

See also: Celiac Disease; Celiac Sprue

Gluten Intolerance
15110 10 Ave. SW, Ste. A
Seattle, WA 98116-1820
(206) 246-6652,
(206) 246- 6531 (fax)
✉info@gluten.net
http://www.gluten.net
1,2,3,4,5,6,7,8

GLUTEN-SENSITIVE ENTEROPATHY

See: Celiac Disease; Celiac Sprue; Gluten Intolerance

GLYCOGEN STORAGE DISEASES

Association for Glycogen Storage Disease
PO Box 896
Durant; IA 52747
(563) 785-6038 (voice/fax)
http://www.agsdus.org
1,2,3,4,6,8

Glycogen Storage Disease List Serve
To register send e-mail to:
LISTSERV@MAELSTROM.STJOHNS.EDU
3

GLYCOGENOSES

See: Glycogen Storage Diseases

GLYCOSPHINGOLIPIDOSES

See: Tay-Sachs Disease

GOLDENHAR SYNDROME

See also: Craniofacial Disorders

Goldenhar Syndrome Research & Information Fund
PO Box 61643
St. Petersburg, FL 33714
(813) 522-5772
(813) 522-5885 (fax)
✉btorman@pbsnet.com
http://www.GOLDENHAR.com
2

GOLDENHAR-GORLIN SYNDROME

See: Goldenhar Syndrome

GOLDFLAM DISEASE

See: Myasthenia Gravis

GONADAL DYGENESIS (45, X)

See: Turner Syndrome

GORLIN-CHAUDHRY-MOSS SYNDROME

See: Ectodermal Dysplasias

GRANULOMA, EOSINOPHILIC

See: Histiocytosis

GRANULOMATOUS DISEASE, CHRONIC

See also: Immune Disorders

Chronic Granulomatous Disease Association Inc.
c/o Mary Hurley
2616 Monterey Rd.
San Marino, CA 91108
(626) 441-4118
✉cgda@socal.rr.com
http://www.cgdassociation.org
1,2,3,4,7,8,9

GRAVES DISEASE

See: Thyroid Disorders

GROENBLAD-STRANDBERG SYNDROME

See: Pseudoxanthoma Elasticum (PXE)

GROUP B STREP

Group B Strep Association
PO Box 16515
Chapel Hill, NC 27516
(919) 932-5344
(919) 932-3657 (fax)
http://www.groupbstrep.org
1,2,3,4,7,8,9

GROWTH DISORDERS

See also: Dwarfism; Short Stature

Human Growth Foundation
997 Glen Cove Ave.
Glen Head, NY 11545
(800) 451-6434
(516) 671-4041
(516) 671-4055 (fax)
✉hgf1@hgfound.org
http://www.hgfound.org
1,2,3,6,8,9; *Spanish materials*

Little People's Research Fund
80 Sister Pierre Dr.
Towson, MD 21204
(800) 232-5773
(410) 494-0055
(410) 494-0062 (fax)
✉lprf@lprf.org
http://www.lprf.org
1,2,8

MAGIC Foundation
1327 N. Harlem Ave.
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808 (fax)
(708) 383-0899
✉mary@magicfoundation.org
http://www.magicfoundation.org
1,2,3,4,5,6,9; *Spanish materials; pen pal program for children*

GROWTH HORMONE DEFICIENCY

See: Growth Disorders

GROWTH RETARDATION, INTRAUTERINE

See: Growth Disorders

GROWTH RETARDATION-ALOPECIA-PSEUDOANODONTIA-OPTIC ATROPHY

See: Ectodermal Dysplasias

GUERIN-STERN SYNDROME

See: Arthrogryposis Multiplex Congenita

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

GUILLAIN-BARRÉ SYNDROME

See also: Autoimmune Disorders

Guillain-Barré Syndrome Support Group of Ontario
c/o M.D.A.C
2345 Yonge St., Ste. 901
Toronto, ON CAN M4P 2E5
(800) 567-2873
(519) 747-5777
(519) 747-5987 (fax)
✉info@brenfile.com
1,5,6,8,9

Guillain-Barre Syndrome Foundation International
PO Box 262
Wynnewood, PA 19096
(610) 667-0131
(610) 667-7036 (fax)
✉GBINT@ix.netcom.com
http://www.guillain-barre.com

GÜNTHER PORPHYRIA

See: *Porphyria*

HADDAD SYNDROME

See: *Central Hypoventilation Syndrome, Congenital*

HAILEY-HAILEY DISEASE

See: *Ichthyosis*

HAIRY ELBOWS DYSPLASIA

See: *Ectodermal Dysplasias*

HALLERMAN-STREIFF SYNDROME

See: *Craniofacial Disorders; Ectodermal Dysplasias; Short Stature*

HALLERVORDEN-SPATZ SYNDROME

Hallervorden-Spatz Syndrome Association
2082 Monaco Ct.
El Cajon, CA 92019-4235
(619) 588-2315
(619) 588-4093 (fax)
http://www.hssa.org

HALLOPEAU-SIEMENS DISEASE

See: *Epidermolysis Bullosa, Dystrophic*

HAND-SCHÜLLER-CHRISTIAN SYNDROME

See: *Histiocytosis*

HAND-SHOULDER SYNDROME

See: *ReflexSympathetic Dystrophy Syndrome*

HARLEQUIN ICHTHYOSIS

See: *Ichthyosis*

HAY-WELLS SYNDROME

See: *Cleft Palate; Craniofacial Disorders; Deaf-Blind; Ectodermal Dysplasias; Hearing Impairments; Visual Impairments*

HAYDEN SYNDROME

See: *Ectodermal Dysplasias*

HEAD INJURY

See: *Brain Injury*

HEARING IMPAIRMENTS

Alexander Graham Bell Association for the Deaf and hard of hearing
3417 Volta Pl. NW
Washington, DC 20007-2778
(202) 337-5220 (voice/TDD)
(202) 337-8314 (fax)
✉lquigley@agbell.org
http://www.agbell.org
1,2,3,4,5,6; *Spanish materials, scholarship program*

American Society for Deaf Children
PO Box 3355
Gettysburg, PA 17325
(800) 942-2732 (voice/TDD)
(717) 334-7922
(217) 334-8808 (fax)
✉asdc1@aol.com
http://www.deafchildren.org
1,2,3,4,5,6,7

American Speech, Language, Hearing Association
10801 Rockville Pike
Rockville, MD 20852
(301) 897-5700
(301) 571-0457 (fax)
http://www.asha.org
1,2,3,6,7,8,9

Auditory-Verbal International
2121 Eisenhower, Ste. 402
Alexandria, VA 22314
(703) 739-1049
(703) 739-0874 (TDD)
(703) 739-0395 (fax)
✉audiverb@aol.com
http://www.auditory-verbal.org
1,2,3,4,6,7

Better Hearing Institute—U.S. and Canada
515 King Street, Suite 420
Alexandria, VA 22314
(800) 327-9355 (voice/TDD)
(703) 684-3391
1,2,4

Cochlear Implant Association, Inc.
5335 Wisconsin Ave. NW
Washington, DC 20015
(202) 895-2781
(202) 895-2782 (fax)
✉76207.3114@compuserve.com
1,2,3,4,5,6,7

Deafness Research Foundation
1225 1 St., Ste. 500
Washington, DC 20005
(800) 829 -5334 (voice/TDD):
(202) 289-5850 (voice/TDD):
http://www.hearinghealth.org
1,2,4,7,8,9

Gallaudet University
Office of Public Relations
800 Florida Ave., NE
Washington, DC 20002-3695
(202) 651-5050
(202) 651-5608 (TDD)
(202) 651-5704 (fax)
✉public.relations@gallaudet.edu
http://www.gallaudet.edu

HEAR Now The Us Program of the Starkey Hearing Foundation
4248 Park Glen Rd.
Minneapolis MN 55416
(800) 648-4327
(952) 828-6946 (fax)
✉nonprofit@starkey.com
1,2,7; *accepts tax-deductible donations of used hearing aids*

John Tracy Clinic for Preschool Deaf Children
806 W. Adams Blvd.
Los Angeles, CA 90007
(800) 522-4582 (voice/TDD)
(213) 748-5481
(213) 747-2924 (TDD)
(213) 749-1651 (fax)
✉mmartindale@johntracy-clinic.org
http://www.johntracyclinic.org
1,2,4; *free correspondence course for preschoolers, Spanish materials*

Lead Line
House Ear Institute
2100 W. Third St., 5th Flr.
Los Angeles, CA 90057
(800) 352-8888 (voice/TDD)
(800) 287-4763 (voice/TDD, Canada only)
(213) 484-2642
(213) 483-4431 (fax)
✉blincoln@hei.org
http://www.hei.org
2,3,4

National Association of the Deaf
814 Thayer Ave., Ste. 250
Silver Spring, MD 20910-4500
(301) 587-1788
(301) 587-1789 (TDD)
(301) 587-1791 (fax)
✉nadinfo@nad.org
http://www.nad.com
1,2,4,5,6,7; *youth program includes Jr NAD clubs and Youth Leadership Camp.*

National Deaf Education Network and Clearinghouse
KDES PAS-6
800 Florida Ave., NE
Washington, DC 20002-3695
(202) 651-5051
(202) 651-5052 (TDD)
(202) 651-5044 (fax)
✉Clearinghouse.Infotogo@gallaudet.edu
http://clerccenter.gallaudet.edu

SEE Center for the Advancement of Deaf Children
PO Box 1181
Los Alamitos, CA 90720
(562) 430-1467 (voice/TDD)
(562) 795-6614 (fax)
✉seectr@aol.com
http://www.seecenter.org
2,4

SHHH: Self Help for Hard of Hearing People
7910 Woodmont Ave.,
Ste. 1200
Bethesda, MD 20814
(301) 657-2248
(301) 657-2249 (TDD)
(301) 913-9413 (fax)
✉National@shhh.org
http://www.shhh.org
1,2,4,5,6

Telecommunications for the Deaf, Inc.
8630 Fenton St., Ste. 604
Silver Spring, MD 20910-3803
(301) 589-3786
(301) 589-3006 (TDD)
(301) 589-3797 (fax)
✉info@tdi-online.org
http://www.tdi-online.org
1,2,6,7

The Canadian Hearing Society
271 Spadina Rd.
Toronto, ON CAN M5R 2V3
(416) 964-9595
(416) 964-0023 (TDD)
(416) 928-2525 (fax)
✉info@chs.ca
http://www.chs.ca
1,2,3,4,5,6,7

The Learning to Listen Foundation
Auditory Verbal Therapy
Phillips House
North York General Hospital
10 Buchan Ct.
Toronto, ON CAN M2J IV2
(416) 491-4648
(416) 491-7215 (fax)
✉westabro@nygh.on.ca
http://www.learningtolisten.org
1,2,3,4,6; *auditory-verbal services for children who are deaf and hard of hearing and their families; professional education*

National Cued Speech Association (NCSA)
23970 Hermitage Rd.
Cleveland, OH 44122-4008
(216) 292-6213 (voice/TDD)
(800) 459-3529 (voice/TDD)
✉cuedspdisc@aol.com
http://www.cuedspeech.org
1,2,3,4,5,6,7

HEART DISORDERS

American Heart Association
7272 Greenville Ave.
Dallas, TX 75231-4596
(800) 242-8721
(214) 706-1179
(214) 706-2139 (fax)
✉inquires@heart.,org
http://www.americanheart.org
2,5,6,7; *Spanish Materials*

CHASER: Congenital Heart Anomalies—Support, Education, & Resources, Inc.
2112 N. Wilkins Rd.
Swanton, OH 43558
(419) 825-5575
(419) 825-2880 (fax)
✉chaser@compuserv.com
✉myer106w@cdc.gov
http://www.csun.edu/~hfmth006/chaser
1,2,3,4,7,9

Children's Heart Association for Support and Education
c/o Cardiac Clinic
Hosp. for Sick Children
Cathy Sikora
555 University Ave.
Toronto, ON CAN S5G 1X8
(416) 813-5848
(416) 813-5582 (fax)
1,2,3,4,8,9

Kids With Heart National Association for Children's Heart Disorders, Inc.
1578 Careful Dr.
Green Bay, WI 54304-2941
(800) 538-5390 (phone/fax-US only)
(920) 498-0058 (phone/fax-outside US)
✉kdswhrt@execpc.com
2,3,4,7,9

HEMANGIOMA

See: *Craniofacial Disorders*

HEMIDYSPLASIA, UNILATERAL

See: *Ichthyosis*

HEMIFACIAL MICROSOMIA

See: *Goldenhar Syndrome*

HEMIHYPERTROPHY

See: *Beckwith-Wiedeman Syndrome*

HEMIPLEGIA, ALTERNATING

See also: Epilepsy; Seizure Disorders

International Foundation for Alternating Hemiplegia of Childhood
239 Nevada St.
Redwood City, CA 94062
(650) 365-5798 (phone/fax)
✉laegan@aol.com
http://www.ahckids.org
1,2,8

HEMISPHERECTOMY

See: *Rasmussen Syndrome*

HEMOLYTIC ANEMIA

See: *Cooley Anemia*

HEMOLYTIC-UREMIC SYNDROME

See: *Kidney Disorders*

HEMOPHAGOCYTIC LYMPHOHISTIOCYTOSIS

See: *Histiocytosis*

HEMOPHAGOCYTIC RETICULOSIS

See: *Histiocytosis*

HEMOPHILIA

National Hemophilia Foundation
116 W.32nd St., 11th Fl.
New York, NY 10001-3212
(800) 424-2634
(212) 328-3700
(212) 328-3777 (fax)
✉info@hemophilia.org
http://www.hemophilia.org
1,2,4,5,6,7,8; *Spanish materials*

World Federation of Hemophilia
1425 Rene Levesque Blvd. W.
Ste. 1010
Montreal, QUE CAN H3G 1T7
(514) 875-7944
(514) 875-8416 (fax)
http://www.wfh.org
✉wfh@wfh.org
1,2,4,6,8; *worldwide referrals; guide for travelers*

HEMORRHAGIC NODULAR PURPURA

See: *Fabry Disease*

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

HEMORRHAGIC TELANGIECTASIA, HEREDITARY (HHT)

Hereditary Hemorrhagic Telangiectasia (HHT) Foundation International, Inc.
PO Box 8087
New Haven, CT 06530
(800) 448-6389
✉hhtinfo@hht.org
http://www.hht.org
1,2,3,5,6,8

HEPATIC DUCTULAR HYPOPLASIA, SYNDROMATIC

See: *Alagille Syndrome*

HEPATOPHOSPHORYLASE DEFICIENCY GLYCOGENOSIS

See: *Glycogen Storage Diseases; Muscular Dystrophy*

HEREDITARY KIDNEY DISEASES

See: *Kidney Diseases, Hereditary*

HEREDITARY LEPTOCYTOSIS

See: Cooley Anemia

HEREDITARY NONPOLYPOSIS COLORECTAL CANCER,

See: Colon Cancer, Hereditary

HERMANSKY-PUDLAK SYNDROME

See also: Albinism & Hypopigmentation; Visual Impairments

Hermansky-Pudlak Syndrome Network Inc.
One South Rd.
Oyster Bay, NY 11771
(800) 789-9477
(516) 922-3440
(516) 922-4022 (fax)
✉hpsnet@worldnet.att.net
http://www.hpsnetwork.org
1,2,3,6,7,9*; Includes help for families struggling with Chediak Higashi syndrome*

HERMAPHRODITISM

See also: Genitalia, Ambiguous

Intersex Society of North America
PO Box 31791
San Francisco, CA 94131
(415) 575-3885
(415) 252-8202 (FAX)
✉info@isna.org
http://www.isna.org
1,2,3,5,7

HERNIA, DIAPHRAGMATIC

CHERUBS The Association Of Congenital Diaphragmatic Hernia Research , Advocacy, and Support.
PO Box 1150
Creedmoor, NC 27522.
(919) 693-8158
(877) 403-1944
(815) 425-9155 (fax)
✉info@cherubs-cdh.org
http://www.cherubs-cdh.org
1,2,3,4,5,6,7,9

HERS DISEASE

See: *Glycogen Storage Diseases; Muscular Dystrophy*

HIRSCHSPRUNG DISEASE

See: *Intestinal Pseudo-Obstruction Syndrome*

HISTIOCYTOSIS

See also: Growth Disorders; Liver Disorders; Lung Diseases; Pituitary Tumors

Histiocytosis Association of America
302 N. Broadway
Pitman, NJ 08071
(800) 548-2758 (US and Canada)
(856) 589-6606
(856) 589-6614 (fax)
✉histiocyte@aol.com
http://www.histio.org
1,2,3,4,6,8,9*; Spanish materials*

HIV

See: *AIDS*

HODGKIN DISEASE

See: *Leukemia*

HOLOPROSENCEPHALY

See also: Craniofacial Disorders

The Carter Centers for Brain Research in Holoprosencephaly and Related Malformations
c/o Dr. Nancy Clegg
Texas Scottish Rite Hospital for Children, Dept. of Neurology
2222 Welborn St.
Dallas, TX 75219
(800) 421-1121 ext. 8411
(214) 559-8411
(214) 559-8383 (fax)
✉nclegg@tsrh.org
http://hpe.stanford.edu
1,2,3,4,6,7,8,9

HUMAN IMMUNODEFICIENCY VIRUS

See: *AIDS*

HUNTER SYNDROME

See: *Mucopolysaccharidosis; Tay-Sachs Disease*

HURLER SYNDROME

See: *Mucopolysaccharidosis; Tay-Sachs Disease*

HURLER/SCHEIE SYNDROME

See: *Mucopolysaccharidosis; Tay-Sachs Disease*

HUTCHINSON-GILFORD SYNDROME

See: *Progeria*

HUTCHINSON-WEBER-PEUTZ SYNDROME

See: *Colon Cancer, Hereditary; Polyposis*

HYDROCEPHALUS

Hydrocephalus Association
870 Market St., Ste. 705
San Francisco, CA 94102
(415) 732-7040
(415) 732-7044 (fax)
✉hydroassoc@aol.com
http://www.neurosurgery.mgh.harvard.edu/ha/
1,2,3,4,6,7*; Spanish materials*

Hydrocephalus Support Group, Inc.
PO Box 4236
Chesterfield, MO 63006-4236
(636) 532-8228
(636) 995-4108 (fax)
✉dhydrobuff@aol.com
1,2,3,4,5,6

National Hydrocephalus Foundation
12413 Centralia Rd.
Lakewood, CA 90715-1623
(562) 402-3523
(562) 924-6666 (fax)
✉hydrobrat@earthlink.net
http://www.nhfonline.org
1,2,3,4,5,7*; videos and cassettes available*

HYDROCEPHALUS, OBSTRUCTIVE

See: *Dandy-Walker Syndrome*

HYPERAMMONEMIA

See: *Urea Cycle Disorders*

HYPERBILIRUBINEMIA

See: *Kernicterus*

HYPERCALCEMIA SYNDROME, INFANTILE, IDIOPATHIC

See: *Williams Syndrome*

HYPERCALCEMIA-SUPRAVALVAR AORTIC STENOSIS

See: *Williams Syndrome*

HYPERCYSTINURIA

See: *Cystinuria*

HYPERGLYCINEMIA WITH KETOACIDOSIS AND LEUKOPENIA

See: *Acidemia, Organic*

HYPERLEXIA

See: *Autism*

Canadian Hyperlexia Association
300 John St.
PO Box 87673
Thornhill, ON CAN L3T 7R3
(905) 886-8364
(905) 886-4624 (fax)
✉cha@ican.net
http://www.home.ican.net/~cha
1,2,3,4,5

American Hyperlexia Association
195 W. Spangler, Ste. B
Elmhurst IL. 60126
(630) 415-2212
(630) 530-5909 (fax)
✉webmaster@hyperlexia.org
http://www.hyperlexia.org
1,3,6

HYPERLIPODEMA

See: *Autoimmune Disorders*

HYPEROXALURIA

See: *Oxalosis & Hyperoxaluria*

HYPERTELORISM/ HYPOSPADIUS SYNDROMES

See: *Opitz Syndrome*

HYPERTHERMIA OF ANESTHESIA

See: *Malignant Hyperthermia*

HYPERTHYROID MYOPATHY

See: *Muscular Dystrophy; Thyroid Disorder*

HYPERURICEMIA–CHOREOATHETOSIS–SELF-MUTILATION SYNDROME

See: *Lesch-Nyhan Disease*

HYPERURICEMIA, HEREDITARY

See: *Lesch-Nyhan Disease*

HYPODONTIA AND NAIL DYSGENESIS

See: *Ectodermal Dysplasias*

HYPOERYTHEMIA, PROGRESSIVE

See: *Anemia, Aplastic*

HYPOGAMMAGLOBULINEMIA

See: *Immune Disorders*

HYPOMELANOSIS OF ITO

See: *Ectodermal Dysplasias; Epilepsy; Incontinentia Pigmenti; Vitiligo*

HYPOMYELINATION

See: *Myelin Disorders*

HYPOPARATHYROIDISM

See also: Panathyroid Disorders

Hypoparathyroidism Association, Inc.
2835 Salmon St.
Idaho Fall, ID 83406
(208) 524-3857
(208) 524-2619 (fax)
http://www.hypopanathyroidism.org
1,2,3

HYPOPIGMENTATION

See: *Albinism & Hypopigmentation; Vitiligo*

HYPOPLASIA OF THE CORPUS CALLOSUM

See: *Agenesis of the Corpus Callosum*

HYPOPLASTIC ANEMIA

See: *Anemia, Aplastic*

HYPOPLASTIC LEFT HEART SYNDROME

See: *Heart Disorders*

HYPOSPADIUS/HYPERTELORISM SYNDROMES

See: *Opitz Syndrome*

HYPOTHYROID MYOPATHY

See: *Muscular Dystrophy; Thyroid Disorders*

HYPOTHYROIDISM, CONGENITAL

See: *Growth Disorders; Thyroid Disorders*

HYPOTONIA, BENIGN CONGENITAL

See: *Spinal Muscular Atrophy*

I-CELL DISEASE

See: *Mucopolysaccharidosis; Tay-Sachs Disease*

ICHTHYOSIFORM ERYTHRODERMA-DEAFNESS-KERATITIS

See: *Ectodermal Dysplasias*

ICHTHYOSIS

FIRST: Foundation for Ichthyosis and Related Skin Types
650 N. Cannon Ave., Ste. 17
Lansdale, PA 19446
(800) 545-3286
(215) 631-1411
(215) 631-1413 (fax)
✉info@scalyskin.org
http://www.scalyskin.org
1,2,3,4,6,7,8,9*; Spanish materials*

IDIOPATHIC THROMBOCYTOPENIA PURPURA (ITP)

See: *Purpura, Idiopathic Thrombocytopenia (ITP)*

IDIOSYNCRATIC PORPHYRIA

See: *Porphyria*

ILEOSTOMY

See: *Ostomy*

ILLNESS, TERMINAL

Children's Hospice International
901 North Pitt St. Suite 230
Alexandria, VA 22314
(800) 2-4-CHILD (242-4453)
(703) 684-0330
(703) 684-0226 (fax)
✉chiorg@aol.com
http://www.chionline.org
1,2,4,6,7

IMMUNE DEFICIENCY

See: *Immune Disorders*

IMMUNE DISORDERS

See also: Autoimmune Disorders

Immune Deficiency Foundation
40 W. Chesapeake Ave.,
Ste. 308
Towson, MD 21204
(800) 296-4433
(410) 321-6647
(410) 321-9165 (fax)
✉idf@primaryimmune.org
http://www.primaryimmune.org
1,2,4,5,6,7,8,9*; Spanish materials*

IMPERFORATE ANUS

See: *Anorectal Malformations*

INCLUSION BODY MYOSTISIS

See: *Immune Disorders*

INCONTINENCE

National Association For Continence
PO Box 8310
Spartanburg, SC 29305
(800) 252-3337
(864) 579-7900
(864) 579-7902 (fax)
✉memberservices@nafc.org
http://www.nafc.org
1,2,7*; Spanish materials*

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

Simon Foundation for Continence
PO Box 815
Wilmette, IL 60091
(800) 237-4666
(847) 864-3913
(847) 864-9758 (fax)
✉simoninfo@simonfoundation.org
http://www.simonfoundation.org
1,2,4,5,6,7; *French and Spanish material*

INCONTINENTIA PIGMENTI

See also: Ectodermal Dysplasias

National Incontinentia Pigmenti Foundation
30 E. 72th St., 16th Fl.
New York, NY 10021
(212) 452-1231
(212) 452-1406 (fax)
✉ipif@ipif.org
http://imgen.bcm.tmc.edu/nipf
1,2,3,4,5,8; *Informational materials in 11 different languages, including English, Spanish, French, Italian, Russian, Portuguese, Chinese, Japanese, and others.*

INCONTINENTIA PIGMENTI ACHROMIANS

See: Ectodermal Dysplasias; Epilepsy; Incontinentia Pigmenti

INDIA RUBBER SKIN

See: Ehlers-Danlos Syndrome

INFANTILE FACIO-SCAPULO-HUMERAL MUSCULAR DYSTROPHY

See: Facio-Scapulo-Humeral Muscular Dystrophy

INFANTILE HYPERCALCEMIA SYNDROME, IDIOPATHIC

See: Williams Syndrome

INFANTILE SPASMS

See: Epilepsy

INTESTINAL NEURONAL DYSPLASIA

See: Intestinal Pseudo-Obstruction Syndrome

INTESTINAL POLYPOSIS

See: Colon Cancer, Hereditary; Polyposis

INTESTINAL POLYPOSIS-CUTANEOUS PIGMENTATION SYNDROME

See: Colon Cancer, Hereditary; Polyposis

INTESTINAL PSEUDO-OBSTRUCTION SYNDROME

International Foundation For Functional Gastrointestinal Disorders (IFFGD)
158 Pleasant St.
North Andover, MA 01845
(800) 394-2747
(978) 685-4477
(978) 685-4488 (fax)
✉: aanastas@iffgd.org
http://www.iffgd.org
1,2,3,4,6,8,9

Association of Gastrointestinal Motility Disorders, Inc.
AGMD International Corporate Hdqtrs.
11 North St.
Lexington, MA 02420
(781) 861-3874
(781) 861-7834 (fax)
✉AGMDInc@aol.com

INTRAHEPATIC BILE DUCT PAUCITY

See: Alagille Syndrome

INTRAUTERINE GROWTH RETARDATION

See: Growth Disorders

ISOVALERIC ACIDEMIA (IVA)

See: Acidemia, Organic

ISOVALERYL-COA CARBOXYLASE DEFICIENCY

See: Acidemia, Organic

JANSKY-BIEL SCHOWSKY DISEASE

See: Batten Disease; Tay-Sachs Disease

JEGHERS SYNDROME

See: Colon Cancer, Hereditary; Polyposis

JERVELL & LANGE-NIELSEN SYNDROME

See: Hearing Impairments; Long Q-T Syndrome

JEUNE SYNDROME

See: Growth Disorders

JOHANSON-BLIZZARD SYNDROME

See: Craniofacial Disorders; Ectodermal Dysplasias; Growth Disorders; Hearing Impairments; Short Stature

JORGENSON SYNDROME

See: Ectodermal Dysplasias

JOUBERT SYNDROME

See also: Apnea, Sleep

Joubert Syndrome Foundation
12348 Summer Meadow Rd.
Rock, MI 49880-9552
(906) 359-4707
(906) 359-4205 (fax)
✉joubert@portup.com
http://www.joubertfoundation.com
1,2,3,4,5,6,9

JUVENILE GOUT-CHOREOATHETOSIS-MENTAL RETARDATION SYNDROME

See: Lesch-Nyhan Disease

KALLMAN SYNDROME

See: Cleft Palate; Growth Disorders; Hearing Impairments; Kidney Disorders

KAST SYNDROME

See: Cancer; Ollier Disease

KEARNS-SAYRE SYNDROME

See: Heart Disorders; Mitochondrial Disorders; Retinitis Pigmentosa; Visual Impairments

KERATITIS FOLLICULARIS SPINULOSA DECALVANS

See: Ectodermal Dysplasias; Ichthyosis

KERATITIS-ICHTHYOSIS-DEAFNESS (KID) SYNDROME

See: Ectodermal Dysplasias; Ichthyosis; Hearing Impairments

KERNICTERUS

See also: Cerebral Palsy

Parents of Infants and Children with Kernicterus (PICK)
517 Brentwood Dr.
Birmingham, AL 35226
Contact: Karen Dixon
(205) 979-2021
✉ktdixon1@home.com
http://www.bilirubin.net
1,2,3,4,6,7,8,9

KETOACIDURIA

See: Maple Syrup Urine Disease

KETOTIC HYPERGLYCINEMIA

See: Acidemia, Organic

KID SYNDROME

See: Ectodermal Dysplasias; Ichthyosis; Hearing Impairments

KIDNEY DISEASES, HEREDITARY

See also: Cystinosis; Kidney Disorders, Hereditary; Oxalosis & Hyperoxaluria

Hereditary Nephritis Foundation
1390 W. 6690 S., #202H
Murray, UT 84123
(801) 262-5901(phone/fax)
http://www.cc.utah.edu/~cla6202/HNF.htm
1,3,4

KIDNEY DISORDERS

See also: Cystinosis; Kidney Diseases, Hereditary; Oxalosis & Hyperoxaluria

American Association of Kidney Patients
100 S. Ashley Dr., Ste. 280
Tampa, FL 33602
(800) 749-2257
(813) 223-7099
(813) 223-0001 (fax)
✉info@aakp.org
http://www.aakp.org
1,2,4,5,6,7,8

American Kidney Fund
6110 Executive Blvd., Ste. 1010
Rockville, MD 20852
(800) 638-8299
(301) 881-3052
(301) 881-0898 (fax)
✉helpline@akfinc.org
http://www.arbon.com/kidney
1,2,6,8; *Spanish materials, financial assistance for treatment-related expenses*

Child & Youth Clinical Trials Network (CYCTN)
Spencer Russ, Acting Director
Cheo-Research Institute
401 Smith Rd.
Ottawa, ON CAN K1H 8L1
(613) 737-4098
(613) 738-4800 (fax)
http://www.cpkdrc.org
2,4

Kidney Foundation of Canada
300-5165 Sherbrooke St. W.
Montreal, PQ CAN H4A IT6
(514) 369-4806
(514) 369-2472 (fax)
✉kathleen@kidney.ca
http://www.kidney.ca
2,3, [illegible] *French/Chinese/* [illegible] *materials*

National Kidney Foundation
30 E. 33rd St., 11th Fl.
New York, NY 10016
(800) 622-9010
(212) 889-2210
(212) 779-0068 (fax)
http://www.kidney.org
1,2,4,5,6,7,8

The PKD Foundation (formerly Polycystic Kidney Research Foundation)
4901 Main St., Ste. 200
Kansas City, MO 64112-2634
(800) 753-2873
(816) 931-2600
(816) 931-8655 (fax)
✉pkdcure@pkdcure.org
http://www.pkdcure.org
1,2,5,6,7,8;
Spanish/French/German/Italian/Japanese materials

KIDNEY STONES

See: Cystinuria

KINKY HAIR DISEASE

See: Menkes Disease

KIRGHIZIAN DERMATOOSTEOLYSIS

See: Ectodermal Dysplasias

KLINEFELTER SYNDROME

49 XXXXY Syndrome Association
10001 NE 74th St.
Vancouver, WA 98662-3801
(360) 892-7547
✉kimbj@juno.com
1,3

Klinefelter's Syndrome Association, Inc. 47, XXX and 47, XYY
PO Box 2119
Loomis, CA 95650
(916) 660-1599
(888) 999-9428 (toll free line)
(916) 660-1899 (fax)
✉info@genetic
http://www.genetic.org
1,2,3,4,5,6,7,8,9; *Spanish materials*

Klinefelter's Syndrome Association of America
N5879 30th Rd.
Pine River, WI 54965
(920) 987-5782
1,2,3,5

KLIPPEL-TRENAUNAY SYNDROME

See also: Nevi, Giant Congenital; Sturge-Weber Syndrome;

Klippel-Trenaunay Support Group
c/o Judy Vessey
5404 Dundee Rd.
Edina, MN 55436
(652) 925-2596
http://www.k-t.org
✉jvessey@qwest.net
1,2,3,4,5,6,9

KLIPPEL-TRENAUNAY-WEBER SYNDROME

See: Klippel-Trenaunay Syndrome

KRABBE DISEASE

See: Leukodystrophy, Tay-Sachs Disease

KUFS DISEASE

See: Batten Disease; Tay-Sachs Disease

KUGELBERG-WELANDER DISEASE

See: Spinal Muscular Atrophy

KUSSMAUL-LANDRY PARAYLSIS

See: Guillain-Barré Syndrome

KYPHOSIS

See: Scoliosis

LACTATE DEHYDROGENASE DEFICIENCY

See: Muscular Dystrophy

LACTIC ACIDOSIS

See also: Glutaric Aciduria, Type I; Metabolic Disorders

Lactic Acidosis Support Group
1620 Mable Ave.
Denver, CO 80229
(303) 287-4953
2,3,4,9

LAMBERT-EATON SYNDROME

See: Muscular Dystrophy

LANDOUZY-DEJERINE MUSCULAR DYSTROPHY

See: Facio-Scapulo-Humeral Muscular Dystrophy

LANDRY ASCENDING PARAYLSIS

See: Guillain-Barré Syndrome

LANGER-GIEDION SYNDROME

See: Ectodermal Dysplasias; Exostoses, Multiple Hereditary

LANGERHANS CELL HISTIOCYTOSIS

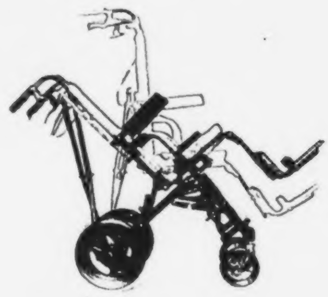
See: Histiocytosis

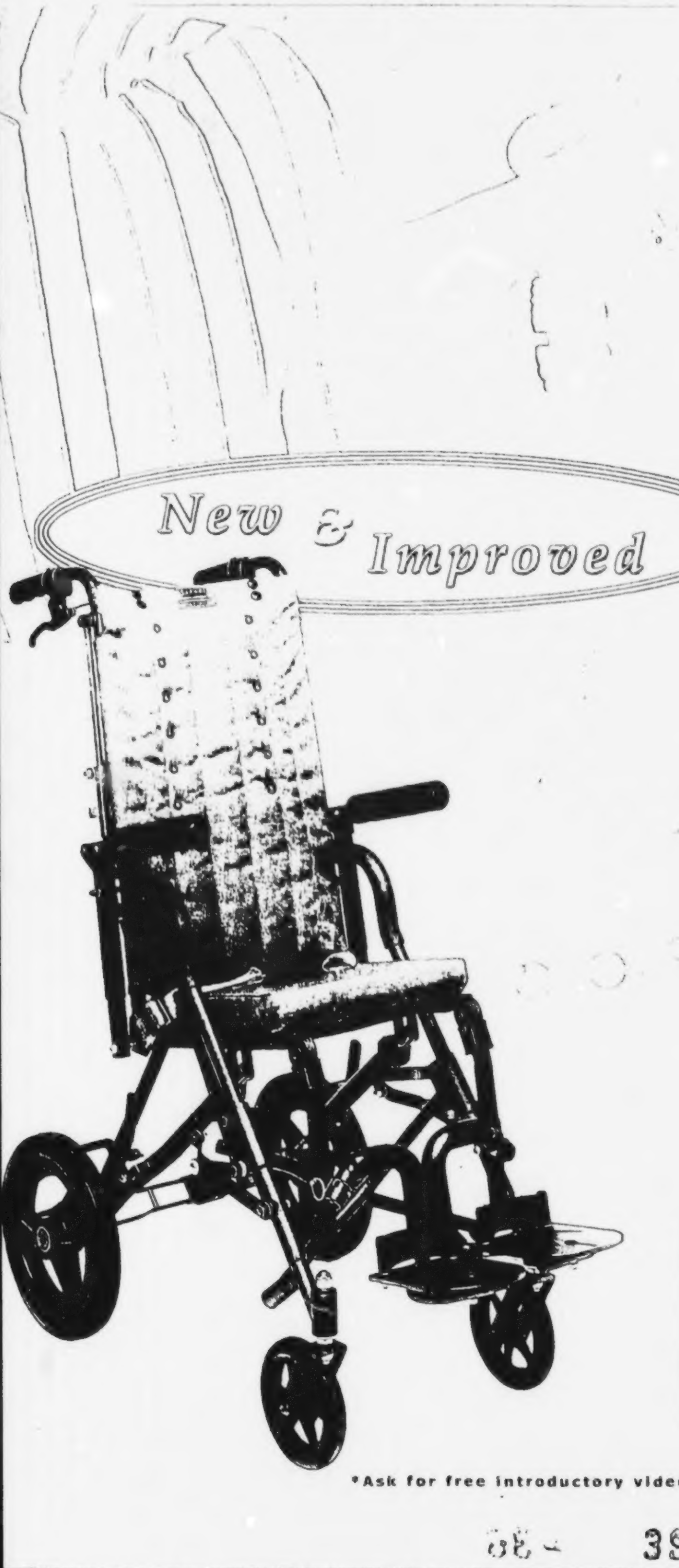
LATEX ALLERGY

Latex Allergy Information Service
176 Roosevelt Ave.
Torrington, CT 06790
(860) 482-6869
(860) 482-2294 (fax)
✉debilan1@cs.com
http://www.latexallergyhelp.com
1,2,4,6

More Smiles

Safari Tilt





When you talk...

we listen

The new and improved Safari chair is something to smile about.

- New instructional video*
- Improved fold
- New style heel loops
- Optional recline, 5 - 45 degrees
- Easy to tilt
- Crash tested

*Ask for free introductory video

Convaid

Circle #44 or visit www.eparent.com/adinfo

PO Box 4209, Palos Verdes, CA 90274 USA ○ Tel 1-888-CONVAID (266-8243) / FAX 310-618-8811 www.convaid.com

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/Health Services
- Degenerative and Aging Service Options
- Nursing Home

Visit us
on the Web:
www.annandale.org

Annandale
VILLAGE

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381
Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation. • Georgia Permit # 067-03-001-01 • Charitable Registration # 01-911713

Circle #22 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

WHY CHILDREN WHO RELY ON GOODNITES ARE MORE INDEPENDENT.

Independence means different things to different people. For children with bladder or bowel control problems, it could just mean getting through the day dry. That's why something as simple as a change in clothing, can, even in a small way, change a child's way of life.

GoodNites® absorbent underpants can help a child become more independent. With GoodNites, accidents won't become catastrophes. So your child will be able to do more. Plus, because they look like real underwear, kids don't mind wearing them. And since they're easy to pull on and off, they can make a child feel more self-reliant.

GoodNites are available in 3 sizes: 45–65 lbs., 65–85 lbs., and 85–125 lbs. That means finding the size that fits your child will no longer be a problem. Plus they have tear-away sides and they're latex-free.

- *Day and nighttime protection*
- *Latex-free*
- *Tear-away sides for easy removal*
- *Three sizes, to fit kids from 45–125 lbs.*

Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS
45 lb & over

For Better Days.

Imagine your child gaining a little more independence just by a change in clothing. For information on how GoodNites can help, and a free sample offer, please visit us at www.goodnites.com/offer

BEST COPY AVAILABLE

®Registered trademark of Kimberly-Clark Corporation. ©2000 KCC.

Circle #81 or visit www.eparent.com/adinfo

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

LAURENCE-MOON SYNDROME

See: *Laurence-Moon-Bardet-Biedl Syndrome*

LAURENCE-MOON-BARDET-BIEDL SYNDROME (LMBBS)

See also: Kidney Disorders, Retinitis Pigmentosa

Laurence-Moon-Bardet-Biedl Syndrome Network
(LMBBS)
Executive Plaza 1
11350 McCormick Rd., Ste. 800
Hunt Valley, MD 21031
(888) 683-5555 (toll free)
(800) 683-5551 (TDD)
(410) 785-1414
(410) 771-9470 (fax)
Attention: Ridia Anderson
✉mmarzullo@blindness.org
http://www.blindness.org
1,2,3

LE JEUNE SYNDROME

See: *Cri Du Chat Syndrome*

LEARNING DISABILITIES

See also: Attention Deficit Disorder, Dyslexia

Learning Disabilities Association of America
4156 Library Rd.
Pittsburgh, PA 15234
(412) 341-1515
(412) 344-0224 (fax)
✉ldanatl@usaor.net
http://www.ldanatl.org
1,2,4,5,6,7; *Spanish materials*

Learning Disabilities Association of Canada
323 Chapel St., Ste. 200
Ottawa, ON CAN K1N 7Z2
(613) 238-5721
(613) 235-5391 (fax)
✉information@ldac-taac.ca
http://www.ldac-taac.ca
1,2,4,5,6,7,8; *French materials*

Learning Disabilities Association of New York City, Inc.
27 West 20th St., Ste. 303
New York, NY 10011
(212) 645-6730
(212) 924-8896 (fax)
2,4

National Center for Learning Disabilities
381 Park Ave. S, Ste. 1401
New York, NY 10016
(888)575-7373
(212) 545-7510
(212) 545-9665 (fax)
http://www.ncld.org
1,2,4,7

Parents of Gifted/LD Students
2420 Eccleston St.
Silver Spring, MD 20902-4925
(301) 986-1422
(301) 681-4884 (fax)
✉jilmeyers@aol.com
http://www.geocities.com/athens/1105/gtld.htm
1,2,3,4,5

Resource for Children with Special Needs, Inc.
200 Park Ave. S., Ste. 816
New York, NY 10003
(212) 677-4650
(212) 254-4070 (fax)
✉info@resourcesnyc.org
http://resourcesnyc.org
2,4

LEIGH'S DISEASE

See: *Lactic Acidosis; Mitochondrial Disorders*

LENZ-PASSARGE DYSPLASIA

See: *Ectodermal Dysplasias*

LEPTOCYTOSIS, HEREDITARY

See: *Cooley Anemia*

LEPTOMENINGEAL ANGIOMATOSIS

See: *Sturge-Weber Syndrome*

LESCH-NYHAN DISEASE

International Lesch-Nyhan Disease Association
11042 Ferndale St.
Philadelphia, PA 19116
(215) 677-4206
2,3

International Lesch-Nyhan Disease Registry
Matheny School and Hospital
Institute, for Research in
Developmental Disabilities
PO Box 339
Peapack, NJ 07977
(908) 234-0618
(908) 234-0963 (fax)
✉research@matheny.org
http://www.matheny.org
2,3,9

Lesch-Nyhan Registry
Dept. of Psychiatry
New York Univ., School of
Medicine
550 First Ave.
New York, NY 10016
(212) 263-6458
(212) 629-9523 (fax)
✉andersnl@is2.nyu.edu

LETTERER-SIWE DISEASE

See: *Histiocytosis*

LEUKEMIA

See also: Bone Marrow Transplant, Cancer

Leukemia Research Fund of Canada
Attn:Maureen E. Thornton
936 The East Mall
Toronto, ON CAN m9B 6J9
(800) 268-2144 (Canada only)
(416) 661-9541
(416) 661-7799 (fax)
✉lrfc@lrfc.org
http://www.leukemia.ca
1,2,4,5,8

Leukemia & Lymphoma Society
1311 Mamaroneck Ave., 3rd Fl
White Plains, NY 10605
(800) 955-4572
(914) 949-5213
(914) 949-6691 (fax)
http://www.leukemia-lymphoma.org
1,2,3,4,5,6,7,8; *Spanish materials*

LEUKODYSTROPHY

See also: Myelin Disorders, Tay-Sachs Disease

United Leukodystrophy Foundation
2304 Highland Dr.
Sycamore, IL 60178
(800) 728-5483
(815) 895-3211
(815) 895-2432 (fax)
✉ulf@tbcnet.com
http://www.ulf.org
1,2,3,4,6,8,9; *Spanish/French materials*

LEUKODYSTROPHY, METACHROMATIC

See: *Leukodystrophy, Tay-Sachs Disease*

LIMB DISORDERS

See also: Amputation

Superkids: A Newsletter for Families and Friends of Children with Limb Differences
60 Clyde St.
Newton, MA 02460-2250
http://www.superkids.org
1,3

LIMB-GIRDLE MUSCULAR DYSTROPHY

See: *Muscular Dystrophy*

LIMIT DEXTRINOSIS

See: *Glycogen Storage Diseases; Muscular Dystrophy*

LIPID HISTIOCYTOSIS

See: *Niemann-Pick Disease*

LIPIDOSIS, CEREBROSIDE

See: *Gaucher Disease*

LIPOFUSCINOSES, NEURONAL CEROID

See: *Batten Disease*

LIPOID HYPERPLASIA, CONGENITAL

See: *Adrenal Disorders*

LIPOMYELOMENINGOCELE

Lipomyelomeningocele Family Support Network
321 Hopewell St.
Birdsboro, PA 19508
(610)582-5937
http://www.home.ptd.net/~ifsn
✉gmcafee@ptd.net

LISSENCEPHALY

See also: Epilepsy

Lissencephaly Network, Inc.
10408 Bitterroot Ct.
Fort Wayne, IN 46804
(219) 432-4310 (voice/fax)
✉lta1@is2.nyu.edu
http://www.lissencephaly.org
1,2,3,4,9

The Lissencephaly Network, Inc.—Canada Division
1549 Regent St.
Regina, SK CAN S4N 1S1
(219) 432-4310
http://www.lissencephaly.org
1,2,3,4,6,8,9; *toy-lending library*

LIVER DISEASE AND TRANSPLANT (PEDIATRICS)

See also: Liver Disorders

Children's Liver Alliance (formerly the Biliary Atresia & Liver Transplant Network BALT)
3835 Richmond Ave., Box 190
Staten Island, NY 10312-3828
(718) 987-6200 (voice/fax)
✉Livers4Kids@earthlink.net
http://www.livertx.org
1,2,3,4,5,6,7,9; *Spanish materials*

LIVER DISORDERS

American Liver Foundation
75 Maiden Ln., Ste. 603
New York, NY 10038-4810
(800) 223-0179,
(800) GO-LIVER,
(888)4-HEP-ABC,
(212) 668-1000,
(212) 483-8179(fax)
✉webmail@liverfoundation.org
http://www.liverfoundation.org
1,2,4,5,7,8,9; *Spanish materials*

Canadian Liver Foundation
2235 Sheppard Ave. E.,
Ste. 1500
Toronto, ON CAN M2J 5B5
(800) 563-5483 (Canada only)
(416) 491-3353
(416) 491-4952 (fax)
✉clf@liver.ca
http://www.liver.ca
1,2,3,4,5,8; *French materials*

LIVER PHOSPHORYLASE DEFICIENCY

See: *Glycogen Storage Diseases; Muscular Dystrophy*

LOBSTEIN DISEASE, TYPE I

See: *Osteogenesis Imperfecta*

LONG QT SYNDROME

See also: Heart Disorders

International Long QT Syndrome Registry
PO Box 653
University of Rochester
Medical Ctr.
Rochester, NY 14642-8653
(716) 275-5391
(716) 473-2751 (fax)
4,9

Sudden Arrhythmia Death Syndromes (SADS) Foundation
508 E. South Temple, Ste. 20
Salt Lake City, UT 84102
(800) 786-7723
(801) 531-0945 (fax)
✉sads@sads.orgt
http://www.sads.org
1,2,3,4,6,8,9; *Spanish materials*

LORDOSIS

See: *Scoliosis*

LOWE SYNDROME

See also: Arthritis; Cystinuria; Glaucoma; Growth Disorders; Kidney Disorders; Metabolic Disorders; Visual Impairments

Lowe Syndrome Association
222 Lincoln St.
W. Lafayette, IN 47906
(765)743-3634
✉info@lowesyndrome.org
http://www.lowesyndrome.org
1,2,3,6,8,9

LOWE-BICKEL SYNDROME

See: *Lowe Syndrome*

LOWE-TERRY-MACHLACHLAN SYNDROME

See: *Lowe Syndrome*

LUNG DISEASES

American Lung Association
1740 Broadway, 14th Fl.
New York, NY 10019
(800) LUNG-USA
(212) 315-8700
(212) 265-5642 (fax)
(212) 315-8872 (fax)
✉info@lungusa.org
http://www.lungusa.org
2,4,5,6,7,8; *Spanish materials*

Canadian Lung Association
Attn: Deirdre Freiheit
3 Raymond St Ste 300
Ottowa, ON CAN K1R 1A3
(613) 564-6411
(613) 747-7430 (fax)
✉info@lung.ca
http://www.lung.ca
2,4,5,6,7

LUPUS ERYTHEMATOSIS

Lupus Foundation of America
1300 Piccard Dr., Ste. 200
Rockville, MD 20850
(888) 385-8787
(301) 670-9292
(301) 670-9486 (fax)
✉lupusinfo@aol.com
http://www.lupus.org
1,2,5,7,8 Spanish materials

SLE Foundation
149 Madison Ave., Ste. 205
New York, NY 10016
(212) 685-4118
(212) 545-1843 (fax)
✉lupus@lupusny.org
http://www.lupusny.org
1,2,3,4,5,6,7,8; *Spanish materials*

Lupus Canada
PO Box 64034
5512 4 St., NW
Calgary, AB CAN T2K 6J1
(800) 661-1468,
(403) 274-5599 (phone & fax)
✉lupuscan@cadvision.com
http://www.lupuscanada.org
2,4,5,6,7,8; *French materials*

LYME DISEASE

American Lyme Disease Foundation, Inc.
Mill Pond Offices
293 Rte. 100
Somers, NY 10589
(914) 277-6970
(914) 277-6974 (fax)
✉inquire@aldf.com
http://www.aldf.com
1,2,4,6,8,9

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

Lyme Disease Foundation
1 Financial Plaza, Gold Bldg.,
18th Fl.
Hartford, CT 06103-2610
(800) 886-5953 (info line)
(860) 525-2000
(860) 525-8425 (voice/fax)
✉lymefnd@aol.com
http://www.lyme.org
1,2,4,6,7; *Spanish materials; May of 2000, in London.*

Lyme Disease Resource Center
PO Box 1423
Ukiah, CA 95482
(707) 468-8460
✉pcm@pacific.net
1,2,4,6,7

LYMPHANGIOMA

AboutFace International
123 Edwards St. Ste 1003
Toronto, ON CAN M5G1E2
(800) 665-3223
(416) 597-2229
(416) 944-2488 (fax)
✉abtface@interlog.com
http://www.interlog.com/abtface
1,2,3,4,5,6,7

LYMPHEDEMA

National Lymphedema Network
Latham Square
1611 Telegraph Ave., Ste. 1111
Oakland, CA 94612-2138
(800) 541-3259
(510) 208-3110 (fax)
✉nln@lymphnet.org
http://www.lymphnet.org
1,2,6,7,9

LYMPHOHISTIOCYTOSIS, FAMILIAL ERYTHROPHAGOCYTIC

See: *Histiocytosis*

LYMPHOHISTIOCYTOSIS, HEMOPHAGOCYTIC

See: *Histiocytosis*

LYMPHOHISTIOCYTOSIS, MALIGNANT

See: *Cancer, Histiocytosis*

LYMPHOMA

See: *Leukemia*

LYSOSOMAL STORAGE DISEASES

See: *Fabry Disease; Gaucher Disease,* Mucopolysaccharidosis, Niemann-Pick Disease; Pompe Disease; Tay-Sachs

---

MACULAR DISEASES

See also: *Retinitis Pigmentosa; Usher Syndrome; Visual Impairments*

Association for Macular Diseases
210 E. 64th St.
New York, NY 10021
(212) 605-3719
(212) 605-3795 (fax)
http://www.macula@macula.org
✉macula@macula.org
1,2,4

Macular Degeneration Foundation
PO Box 9752
San Jose, CA 95157
(888) 633-3937
(408) 260-1335
(408) 260-1336
✉eyesight@eyesight.org
http://www.eyesight.org
1,2,4,9

Stargardt Macular Dystrophy and Other Juvenile Macular Dystrophies Self Help Network
c/o Macular Degeration
International
6700 N. Oracle Rd, Ste. 505
Tucson, AZ 85704
(800) 393-7634
(520) 797-2525
(520) 797-8018 (fax)
✉info@maculardegeneration.org
http://www.macular-degeneration.org
1,2,3,4,6,8

MACULAR DYSTROPHIES, JUVENILE

See: *Macular Diseases*

MAFFUCCI SYNDROME

See: *Cancer; Ollier Disease*

MALE SEX CHROMOSOME DISORDERS

See *Klinefelter Syndrome*

MALIGNANT HYPERTHERMIA

Malignant Hyperthermia Association
200 Elizabeth St.
CCRW, Rm. 2-834
Toronto, ON CAN M5G 2C4
(416) 340-3238
(416) 340-4960 (fax)
http://www.mhacanada.org
1,2

Malignant Hyperthermia Association of the United States
39 East State St.
PO Box 1069
Sherburne, NY 13460
(800) 986-4287,
(607) 674-7901,
(800) 674-7910 (fax)
✉mhaus@norwich.net
http://www.mhaus.org
1,2,9; *Spanish/Italian materials*

MANDIBULOFACIAL DYSOSTOSIS

See: *Nager & Miller Syndromes; Treacher Collins Syndrome*

MANNOSIDOSIS

See: *Tay-Sachs Disease*

MAPLE SYRUP URINE DISEASE

See also: *Acidemia, Organic; Metabolic Disorders*

Maple Syrup Urine Disease Family Support Group
5720 Buckfield Ct.
Fort Wayne, IN 46804
(219) 436-0137
1,2,3,6,9; *parent-professional network*

MARDEN-WALKER SYNDROME

See: *Cleft Palate; Connective Tissue Disorders; Growth Disorders*

MARFAN SYNDROME

See also *Connective Tissue Disorders, Heart Disorders, Scoliosis*

Canadian Marfan Association
Centre Plaza Postal Outlet
128 Queen St., S.
PO Box 42257
Mississauga, ON L5M 4Z0
(905) 826-3223
(905) 826-2125 (fax)
✉info@marfan.ca
http://www.marfan.ca
1,2,3,4,5,6,8,9

National Marfan Foundation
382 Main St.
Port Washington, NY 11050-3121
(800) 8MARFAN [862-7326]
(516) 883-8712
(516) 883-8040 (fax)
✉staff@marfan.org
http://www.marfan.org
1,2,3,4,5,6,7,8

MARKER X SYNDROME

See: *Fragile X Syndrome*

MARTEAUX-LAMY SYNDROME

See: *Mucopolysaccharidosis: Tay-Sachs Disease*

MARSHALL SYNDROME, TYPE I

See: *Ectodermal Dysplasia*

MARTIN-BELL SYNDROME

See: *Fragile X Syndrome*

MAST CELL DISEASE, SYSTEMIC

Mastocytosis Society
433 E. 300 S.
Spanish Fork, UT 84660-2147
(801) 798-2032
(801) 794-2980 (fax)
✉cybermom@uswest.net
✉BillA@Mastocytosis.com
http://www.mastocytosis.com
1,2,5,6

MCARDLE DISEASE

See: *Glycogen Storage Diseases; Muscular Dystrophy*

MCCUNE-ALBRIGHT SYNDROME

See also: *Growth Disorders*

MAGIC Foundation
McCune-Albright Syndrome
Division
1327 N. Harlem Ave.
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808
(708) 383-0899 (fax)
✉mary@magicfoundation.org
http://www.magicfoundation.org
1,2,3,4,6; *Spanish materials, pen pal program for children*

MEDITERRANEAN ANEMIA

See: *Cooley Anemia*

MEDIUM-CHAIN ACYL-COA DEHYDROGENASE DEFICIENCY (MCAD)

See: *Fatty Oxidation Disorder*

MEDULLOBLASTOMA, HEREDITARY

See: *Brain Tumors*

MEERKEREN-EHLERS-DANLOS SYNDROME

See: *Ehlers-Danlos Syndrome*

MEIGE DISEASE

See: *Lymphedema*

MELANOLEUCODERMA ECTODERMAL DYSPLASIAS

See: *Colon Cancer, Hereditary; Polyposis*

MELAS SYNDROME

See: *Growth Disorders, Lactic Acidosis, Mitochondrial Disorders*

MELNICK NEEDLES SYNDROME

See: *Growth Disorders*

MEN SYNDROME I

See: *Multiple Endocrine Neoplasia I*

MENIERE'S SYNDROME

See: *Balance Disorders & Dizziness*

MENINGEAL CAPILLARY ANGIOMATOSIS

See: *Sturge-Weber Syndrome*

MENKES DISEASE

See also: *Liver Disorders; Metabolic Disorders*

Corporation for Menkes Disease
5720 Buckfield Ct.
Fort Wayne, IN 46804
(219) 436-0137 (phone/fax)
1,2,3,6,9; *Parent-professional network.*

MENTAL ILLNESS

See also: *Mental Retardation/Mental Illness*

Canadian Mental Health Association
2160 Yonge St.
Toronto, ON CAN M4S 2Z3
(416) 484-7750
(416) 484-4617 (fax)
✉cmhanat@interlog.com
http://www.cmha.ca
1,2; French materials

Family Network on Disabilities of Florida
2735 Whitney Rd.
Clearwater, FL 33760
(800) 825-5736 (FL only)
(727) 523-1130
(727) 523-8687 (fax)
✉fnd@fndfl.org
http://www.fndfl.org
1,2,3,4,5,6,7

Federation of Families for Children's Mental Health
1101 King St., Ste. 420
Alexandria, VA 22314
(703) 684-7710
(703) 836-1040 (fax)
✉ffcmh@ffcmh.org
http://www.ffcmh.org
1,2,3,4,5,6,7; *Spanish materials*

Mental Health Association of Colorado
6795 E. Tennessee Ave.,
Ste. 425
Denver, CO 80224
(303) 377-3040
(303) 377-4920 (fax)
http://www.MHAcolorado.org
1,2,4

National Alliance for the Mentally Ill
Colonial Place Three
2107 Wilson Blvd., Ste. 300
Arlington, VA 22201
(703) 524-7600
(703) 524-9094 (fax)
✉NAMIOFFC@aol.com
http://www.nami.org
1,2,4,5,6,7

National Mental Health Association
1021 Prince St.
Alexandria, VA 22314-2971
(800) 969-6642
(703) 683-9226 (FAX)
✉infoctr@nmha.org
http://www.nmha.org
1,2,4,5,6,7

National Mental Health Services Knowledge Exchange Network (KEN)
PO Box 42490
Washington, DC 20015
(800) 789-2647
(301) 984-8796 (fax)
✉ken@mentalhealth.org
http://www.mentalhealth.org

Parents & Children Coping Together-PACCT
PO Box 26691
Richmond, VA 23261-6691
(800).477-0946
(804) 559-6833
(804) 559-6835 (fax)
✉pacct@richmond.infi.net

The Parent Connection
PO Box 0
Santa Fe, TX 77510
(800) 839-8876
(409) 756-8321
(409) 925-7773 (fax)

Utah Parent Center
2290 E. 4500 S., Ste. 110
Salt Lake City, UT 84117
(800) 468-1160 (UT only)
(801) 272-1051
(801) 272-8907 (fax)
✉upc@inconnect.com

MENTAL RETARDATION

See also: *Mental Illness; Mental Retardation/ Mental Illness*

The Arc of the United States
1010 Wayne Ave., Ste. 650
Silver Spring, MD 20910
(800) 433-5255
(301) 565-3842
(301) 565-3843 (fax)
✉info@thearc.org
http://www.TheArc.org/
1,2,4,5,6,7,8; *Spanish materials*

Bethphage Developmental Disabilities
2245 Midway Rd., Ste. 300
Carrolton, TX 75006
(972) 866-9989
(972) 991-0834(FAX)
✉donahue@bethphage.org
http://www.bethphage.org
1,2,4

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

Bethphage
The Lind Center, Ste. A
4980 S 118th St.
Omaha, NE 68137-2220
(402) 896-3884
(402) 896-1511 (fax)
✉mburke@bethphage.org
http://www.bethphage.org
1,2,4; *children and adult family services; adult foster care*

Canadian Association for Community Living & The Roeher Institute
4700 Keele St.
Kinsmen Bldg., York University
North York, ON CAN M3J 1P3
(416) 661-9611
(416) 661-2023 (TDD)
(416) 661-5701 (fax)
✉info@roeher.ca
✉info@cacl.ca
http://www.cacl.ca
1,2,4,5,6,7; *French materials*

People First International
PO Box 12642
Salem, OR 97309
(503) 362-0336
(503) 587-8459 (fax)
✉heathd@open.org
http://www.people1.org
1,2,4,6,8; *leadership/self advocacy training*

Voice of the Retarded
5005 Newport Dr., Ste. 108
Rolling Meadows, IL 60008
(847) 253-6020
(847) 253-6054 (fax)
✉vor@compuserve.com
http://www.vor.net
1,2,3,4,5,6,7

MENTAL RETARDATION/MENTAL ILLNESS

See also: Mental Illness; Mental Retardation

(AAMR) American Association on Mental Resources
444 N Capitol St., Ste. 846
Washington, DC 20001
(800) 424-3688
(202) 387-1968
(202)387-2193 (fax)
✉aamr@access.digex.net
http://www.aamr.org
1,2,4,5,6

Developmental Disabilities Nurses Association (DDNA)
P.O. Box 2749
Eugene, OR 97402
(800) 888-6733
(541) 485-7372 (fax)
✉ddnahq@aol.com
http://www.ddna.org
1,2,4,5,6,8

National Association of the Dually Diagnosed (NADD)
132 Fair St.
Kingston, NY 12401
(800) 331-5362
(845) 331-4336
(846) 331-4569 (fax)
✉thenadd@aol.com
http://www.thenadd.org
1,2,3,4,5,6,7; *National, informational, and Regional Conferences'*

MERRF SYNDROME

See: Myoclonus; Mitochondrial Disorders

METABOLIC DISORDERS

See also: Acidemia, Organic; Galactosemia, Lactic Acidosis; Maple Syrup Urine Disease; Neurotransmitter Diseases, Pediatric; Niemann-Pick Disease; Phenylketonuria (PKU)

Metabolic Information Network
PO Box 670847
Dallas, TX 75367-0847
(800) 945-2188 (USA/Canada)
(214) 696-2188
(800) 955-3258 (fax, USA/ Canada)
(214) 696-3258 (fax)
✉mizesg@ix.netcom.com
1,9

Climb
The Quadrangle Crewe Hall
Weston Road, Crewe
Cheshire, UK CW1 6UR
(44)870700326
(44)8707700327fax)
✉info@climb.org.uk
http://www.climb.org.uk
1,2,3,4 *(in UK);*
5,6,7,8;9, *English, French, German, Spanish materials*

The World Life Foundation
PO Box 571
Bedford, TX 76095-0571
(800) 289-5433
(817) 285-0216 (fax)
✉loubaum@airmail.net
Offers air transport for client and one parent to facility for metabolic disorders treatment.

METACHROMATIC LEUKODYSTROPHY

See: Leukodystrophy; Tay-Sachs Disease

METAPHYSEAL DYSOSTOSIS, TYPE B IV

See: Shwachman Syndrome

METHYLMALONIC ACIDEMIA

See: Acidemia, Organic

MICROCEPHALY

FACES–The National Craniofacial Association
PO Box 11082
Chattanooga, TN 37401
(800) 332-2373
(423) 266-1632
(423) 267-3124 (fax)
✉Faces@mindspring.com
http://www.faces-cranio.org
1,2,3,6,9; *financial assistance for medical-related travel*

Genetic Alliance
4301 Connecticut Ave. NW, Ste. 404
Washington, DC 20008-2304
(202) 966-5557
(202) 966-8553 (fax)
(800) 336-GENE (4363) helpline
✉info@geneticalliance.org
http://www.geneticalliance.org
1,2,3,4,6,7,9; *Spanish materials.*

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave.
White Plains, NY 10605
(888) 663-4637
(914) 997-4410(fax)
✉resourcecenter@modimes.org
http://www.modimes.org
2,5,7,8

National Institute of Neurological Disorders & Stroke
PO Box 5801
Bethesda, MD 20824
(800) 352-9424
(301) 496-5751
(301) 402-2186 (fax)
http://www.ninds.nih.gov

MICROPHTHALMIA

See: Anophthalmia; Visual Impairments

MICROSOMIA, HEMIFACIAL

See: Craniofacial Disorders; Goldenhar Syndrome

MICROTIA

See also: Craniofacial Disorders

Microtia-Atresia Support Group
c/o Jack Gross
307 Seventh Avenue # 2306
New York, NY 10001
(212) 947-0770
(212) 714-1224 (fax)
✉GrossInsCo@aol.com
3

MIKAELIAN SYNDROME

See: Ectodermal Dysplasias

MILLER SYNDROME

See: Nager & Miller Syndromes

MILLER-DIEKER SYNDROME

See: Lissencephaly

MILLER-FISCHER SYNDROME

See: Guillain-Barré Syndrome

MILROY DISEASE

See: Lymphedema

MITOCHONDRIAL DISORDERS

United Mitochondrial Disease Foundation (UMDF)
PO Box 1151
Monroeville, PA 15146-1151
(412) 793-8077
(412) 793-6477 (fax)
✉umdf@nb.net
info@umdf.org
1,2,3,4,5,6,7,8,9

MITOCHONDRIAL MYOPATHY

See: Mitochondrial Disorders; Muscular Dystrophy

MOEBIUS SYNDROME

See also: Craniofacial Disorders; Limb Disorders

The Moebius Syndrome News
PO Box 147
Pilot Grove, MO 65276
(660) 834-3406
✉vmccarrell@mid.mo-net
http://www.ciaccess.com/moebius
1,2,3,4,5,6,7,9

Moebius Syndrome Support Group
38883 Fox Holm Dr.
Palmdale, CA 93551
(805) 267-2570 (voice/fax)
✉lorit@netport.com
http://www.wincom.net/moebius/
1,2,3,6,8,9

MONOSOMY X

See: Turner Syndrome

MORQUIO SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

MORVAN DISEASE

See: Syringomyelia

MOTOR-SENSORY NEUROPATHY, HEREDITARY

See: Charcot-Marie-Tooth Disease

MOYAMOYA DISEASE

See: Stroke; Vascular Malformations

MUCOLIPIDOSES

See: Mucopolysaccharidosis, Mucolipidosis Type IV; Tay-Sachs Disease

MUCOLIPIDOSIS TYPE IV

See also: Mucopolysaccharidosis; Tay-Sachs Disease; Visual Impairments

ML4 Foundation
719 East 17th St.
Brooklyn, NY 11230
(718) 434-5067
(718) 859-7371 (fax)
✉ml4@aol.com
http://www.ml4.org
1,2,3,4,5,7,8,9

MUCOPOLYSACCHARIDOSIS

See also: Metabolic Disorders; Tay-Sachs Disease

The National Mucopolysaccharidosis (MPS) Society
102 Aspen Dr.
Downingtown, PA 19335
(610) 942-0100
(610) 942-7188 (fax)
✉presmps@aol.com
http://www.mpssociety.org
1,2,3,4,5,6,8,9; *Spanish materials*

Little People of America
National Headquarters
Box 745
Lubbock, Texas 79408
(888) LPA-2001 (572-2001) (voice/fax; call first)
(806) 797-8830 (voice/fax; call first) Engl./Span.
✉LPADataBase@juno.com
http://www.lpaonline.org
1,2,3,5,6; *Spanish materials*

MUCOSULFATIDOSIS

See: Hearing Impairments; Ichthyosis; Leukodystrophy, Tay-Sachs Disease

MULTIPLE CARBOXYLASE DEFICIENCY

See: Metabolic Disorders

MULTIPLE ENDOCRINE NEOPLASIA I

See also: Adrenal Disorders; Diabetes Mellitus; Thyroid Disorders

Multiple Endocrine Neoplasia I
c/o Mrs. Cathy McMillan-Fitch
Box 100
Meota, SK CAN S0M 1X0
(306) 892-2080 (voice/fax)
✉hockey_freak99@hotmail.com
1,2,3

MULTIPLE SCLEROSIS

Multiple Sclerosis Society of Canada
250 Bloor St. E, Ste. 1000
Toronto, ON CAN M4W 3P9
(800) 268-7582 (nearest division office)
(416) 922-6065
(416) 922-7238 (fax)
✉info@mssociety
http://www.mssociety.ca
1,2,4,5,6,7,8

National Multiple Sclerosis Society
733 3rd Ave., 6th Fl.
New York, NY 10017-3288
(800) 344-4867
(212) 986-3240
(212) 986-7981 (fax)
✉nat@nmss.org
http://www.nmss.org
1,2,4,5,8; *Spanish materials*

MULTIPLE SULFATASE DEFICIENCY

See: Hearing Impairments; Ichthyosis; Leukodystrophy; Tay-Sachs Disease

MUSCLE PHOSPHOFRUCTOKINASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

MUSCLE PHOSPHORYLASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

MUSCULAR ATROPHY, PERONEAL

See: Charcot-Marie-Tooth Disease

MUSCULAR DYSTROPHY

See also: Facio-Scapulo-Humeral Muscular Dystrophy; Ventilator Use

Duchenne Parent Project
4785 Emerald Way
Middletown, OH 45042
(800) 714-KIDS (5437)
(513) 424-0696
(513) 425-9907(fax)
✉patfurlong@aol.com
http://www.parentdmd.org

MUSCULAR DYSTROPHY, DEJERINE-LANDOUZY

See also: Facio-Scapulo-Humeral Muscular Dystrophy; Ventilator Use

Muscular Dystrophy Association
3300 E. Sunrise Dr.
Tucson, AZ 85718-3208
(800) 572-1717
(520) 529-2000
(520) 529-5300 (fax)
✉mda@mdausa.org
http://www.mdausa.org
1,2,4,5,7,8,9

Muscular Dystrophy Association of Canada
2345 Yonge St., Ste. 901
Toronto, ON CAN M4P 2E5
(800) 567-2873 (Canada only)
(416) 488-2699 ext. 160
(416) 488-0107 (fax)
✉motter@mdac.ca
http://www.mdac.ca
1,2,3,4,5,6,7,8; *French materials*

Muscular Dystrophy Family Foundation Inc.
2330 N. Meridian St.
Indianapolis, IN 46208-5730
(800) 544-1213
(317) 923-MDFF (6333)
(317) 923-6334 (fax)
✉mdff@mdff.org
http://www.mdff.org
1,2,3,4,7

Society for Muscular Dystrophy Information International
PO Box 479
Bridgewater, NS CAN B4V 2X6
(902) 685-3961
(902) 685-3962 (fax)
✉smdi@aura.com.com
http://www.auracom.com/~smidi/index.html
1,2,4

MUSCULAR DYSTROPHY, FACIO-SCAPULO-HUMERAL

See: *Facio-Scapulo-Humeral Muscular Dystrophy*

MYASTHENIA GRAVIS

Myasthenia Gravis Foundation of America,Inc
5841 Cedar Lake Road,
Suite 204
Minneapolis, MN 55416
(800) 541-5454
(952) 545-6073 (fax)
✉myastheniagravis@msn.com
http://www.myasthenia.org
1,2,4,5,6,7,8,9; *Spanish materials*

MYASTHENIC SYNDROME OF LAMBERT-EATON

See: *Charcot-Marie-Tooth Disease*

MYELIN DISORDERS

See also: *Leukodystrophy,*

The Canadian Myelin Research Initiative
c/o Julie and Wayne Simmons
4330 Spinningdale Ct.
Mississauga, ON CAN L5M 3J8
(905) 567-8843
(905) 567-9189 (fax)
✉myelin@interlog.com
2,6,7,8,9

The Myelin Messenger
7320 N. Stable Ln.
Prescott, AZ 86305
(520) 776-7556
1,3

The Myelin Project
2001 Pennsylvania Ave. NW
Ste. 225
Washington, DC 20006-1850
(202) 452-8994
(202) 785-9578 (fax)
✉myelin@erols.com
http://www.myelin.org/
1,2,8; *Italian/French/German/Danish/Spanish materials.*

MYELODYSPLASIA

See: *Anemia, Aplastic*

MYELOMA

See also: *Cancer, Leukemia*

International Myeloma Foundation
12650 Riverside Dr., Ste. 206
North Hollywood, CA 91607
(800) 452-2873
(818) 487-7455
(818) 487-7454 (fax)
✉theimf@myeloma.org
http://www.myeloma.org
1,2,3,4,6,7,8

MYELOMA, MULTIPLE

See: *Myeloma*

MYELOSYRINGOSIS

See: *Syringomyelia*

MYOADENYLATE DEAMINASE DEFICIENCY

See: *Muscular Dystrophy*

MYOCLONUS

See: *Epilepsy; Opsoclonus-Myoclonus Syndrome*

Myoclonus Families United
155 E. 35th Street
Brooklyn, NY11234
(718) 252-2133

Myoclonus Research Foundation
200 Old Palisade Road, Suite 17D
Fort Lee, NJ 07024
(201) 585-0770
http://www.myoclonus.com

MYODENYLATE DEAMINASE DEFICIENCY

See: *Muscular Dystrophy*

MYOPATHIES, CONGENITAL

See: *Myotubular Myopathy, X-Linked*

MYOPATHY, CENTRONUCLEAR

See: *Myotubular Myopathy, X-Linked; Muscular Dystrophy*

MYOPATHY, HYPERTHYROID

See: *Muscular Dystrophy; Thyroid Disorders*

MYOPHOSPHORYLASE DEFICIENCY

See: *Glycogen Storage Diseases*

MYOSITIS

See also: *Autoimmune Disorders*

National Myositis Association
7720B El Camino Real, Ste. 367
Rancho La Costa, CA 92009
(800) 230-0441
(619) 436-2185
1,2,3,4,5,9

MYOSITIS OSSIFICANS

See: *Fibrodysplasis Ossificans Progressiva*

MYOTONIA, CONGENITA

See: *Muscular Dystrophy*

MYOTUBULAR MYOPATHY, X-LINKED

See also: *Muscular Dystrophy*

Myotubular Myopathy Resource Group
2602 Quaker Dr.
Texas City, TX 77590
(409) 945-8569
✉gscoggin@aol.com
http://www.mtmrg.org
1,2,3,9

MYXEDEMA

See: *Thyroid Disorders*

N-ACETYL GLUTAMATE SYNTHETASE (NAGS) DEFICIENCY

See: *Urea Cycle Disorders*

NAEFELI-FRANCESCHETTI-JADASSOHN DYSPLASIA

See: *Ectodermal Dysplasias*

NAEGELI-FRANCESCHETTI-JADASSOHN SYNDROME

See: *Incontinentia Pigmenti*

NAGER & MILLER SYNDROMES

See also: *Craniofacial Disorders; Hearing Impairments, Limb Disorders*

Foundation for Nager and Miller Syndromes (FNMS)
1827 Grove St. #2
Glenview, IL 60025-2913
(800) 507-3667
(847) 724-6449 (fax)
✉fnms@interaccess.com
http://www.fnms.net
1,2,3,4,6,8

NASAL ENCEPHALOCELE

See: *Craniofacial Disorders*

NEMALINE MYOPATHY

See: *Muscular Dystrophy*

NEPHRITIS

See: *Kidney Diseases, Hereditary, Fetal Alcohol Syndrome*

NEUROFIBROMATOSIS

See also: *Acoustic Neuroma; Hearing Impairments; Visual Impairments*

National Neurofibromatosis Foundation
95 Pine St., 16th Fl.
New York, NY 10005
(800) 323-7938
(212) 344-6633
(212) 747-0004 (fax)
✉nnff@nf.org
http://www.nf.org

Neurofibromatosis, Inc
8855 Annapolis, Ste. 110
Lanham, MD 20706-2924
(800) 942-6825
(301) 577-8984
(301) 577-0016 (fax)
✉nfinc1@aol.com
http://www.nfinc.org
1,2,4,5,7,8

NEUROLOGICAL DISORDERS

Association for Comprehensive Neurotherapy Latitudes
PO Box 210848
Royal Palm Beach,
FL 33421-0848
(561) 798-0472,
(561) 798-9820 (fax)
✉acn@latitudes.org
http://www.latitudes.org
1,2

Children's Neurobiological Solutions
1726 Franceschi Road
Santa Barbara, CA 93103
(866) 267.5580 or
(805) 965.8838
http://www.cnsfoundation.org
✉info@cnsfoundation.org
8

The Colleen Giblin Foundation for Children's Neurological & Cancer-Related Research
690 Kinderkamack Rd.
Oradell, NJ 07645
(201) 262-2463
(201) 262-6442 (fax)
cgf01@aol.com
http;//www.colleengiblinfound.org
3,8,9; *Funds research in neurological and cancer-related conditions in children including: cancers of the brain; spinal disorders; neuro-metabolic diseases; seizure disorders; and complications from AIDS and fetal exposure to chemical substances.*

NEUROMETABOLIC DISORDERS

See: *Metabolic Disorders*

NEURONAL CEROID LIPOFUSCINOSES

See: *Batten Disease*

NEUROPATHY, AUDITORY

See: *Kernicterus*

NEUROPATHY, HEREDITARY, SENSORY MOTOR

See: *Charcot-Marie-Tooth Disease*

NEUROPATHY, PERIPHERAL

See: *Charcot-Marie-Tooth Disease*

NEUROTRANSMITTER DISEASES, PEDIATRIC

Pediatric Neurotransmitter Disease Association
6 Nathan Dr.
Plainview, NY 11803
(516) 937-0049
✉PND@pndassoc.org
http://www.pndassoc.org
1,2,3,6,7,8,9

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

NEUTROPENIA

Neutropenia Support Assoc., Inc.
PO Box 243
905 Corydon Ave.
Winnipeg, MB CAN R3M 3S7
(800) 663-8876;
(204) 489-8454
✉stevensl@neutropenia.ca
http://www.neutropenia.ca
1,2,3,4,5,6,7; *Promotes chapter development and involvement with the Neutropenia SCN International Registry French materials*

Neutropenia SCN International Registry
Puget Sound Plaza
1325 4th Ave., Ste. 620
Seattle, WA 98101-2509
(800) 726-4463
(206) 543-9749
(206) 543-3668 (fax)
✉registry@u.washington.edu
http://www.depts.washington.edu/registry
1,2

NEUTROPENIA-PANCREATIC INSUFFICIENCY

See: *Shwachman Syndrome*

NEVI, GIANT CONGENITAL

See also: *Craniofacial Disorders; Ichthyosis; Klippel-Trenaunay Syndrome; Sturge-Weber Syndrome*

Nevus Network
PO Box 1981
Woodbridge, VA 22195
(703) 492-0253,
(405) 377-3403
✉nevusnet@bigfoot.com
http://www.nevusnetwork.org
1,2,3,5,9; *French/Spanish materials*

NEVILLE DISEASE

See: *Niemann-Pick Disease*

NEVO SYNDROME

See: *Sotos Syndrome*

NIEMANN-PICK DISEASE

See also: *Ataxia, Metabolic Disorders; Tay-Sachs Disease*

National Niemann-Pick Disease Foundation, Inc.
P.O Box 49; 415 Madison Avenue
Fort Atkinson, WI 53538
(920) 563-0930
(877) CURE-NPC (287-3672)
(920) 563-0931 (fax)
✉webmaster@nnpdf.org
nnpdf@cident.com
http://www.nnpdf.org
1,2,3,4,6,7,8

Ara Parseghian Medical Research Foundation
1760 E. River Rd., Ste. 115
Tucson, AZ 85718
(520) 577-5106
(520) 577-5212 (fax)
✉victory@parseghian.org
http://www.parseghian.org
1,2,3,6,7,8.

NONKETOTIC HYPERGLYCINEMIA

See: *Acidemia, Organic*

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

NOONAN SYNDROME

See also: Growth Disorders; Heart Disorders; Malignant Hyperthermia; Williams Syndrome

(TNSSG) Noonan Syndrome Support Group, Inc.
PO Box 145
Upperco, MD 21155
(888) 686-2224
(410) 374-5245
✉wandar@bellatlantic.net
http://www.noonansyndrome.org
1,2,3,6

NORMAN-ROBERTS SYNDROME

See: Lissencephaly

NORRIE DISEASE

See also: Hearing Impairments; Visual Impairments

Norrie Disease Foundation
Developmental Neurogenetics Unit
Mass General Hospital
CNY #6217
149 13 St.
Charlestown, MA 02129
(617) 726-5718
(617) 724-9620 (fax)
✉sims@helix.mgh.harvard.edu
http://www.neuro.mgh.harvard.edu
2,3,4

NUTRITION

The Oley Foundation
214 Hun Memorial A-28
Albany Medical Center
Albany, NY 12208
(800) 776-OLEY (6539)
(518) 262-5079
(518) 262-5528
✉bishopj@mail.amc.edu
http://www.oley.org
1,2,3,6,7.

NYHAN SYNDROME

See: Lesch-Nyhan Syndrome

OAV SYNDROME

See: Goldenhar Syndrome

OBSESSIVE COMPULSIVE DISORDER

OC Foundation
337 Notch Hill Rd.
North Branford, CT 06471
(203) 315-2190
(203) 315-2196 (fax)
✉info@ocfoundation.org
http://www.ocfoundation.org
1,2,3,4,5,6,7,8

OBSTRUCTIVE HYDROCEPHALUS

See: Dandy-Walker Syndrome

OCULO-AURICULO-VERTEBRAL SPECTUM

See: Goldenhar Syndrome

OCULOCEREBRORENAL SYNDROME

See: Lowe Syndrome

OCULODENTODIGITAL SYNDROME; TYPE I & II

See: Ectodermal Dysplasias

OCULOOSTEOCUTANEOUS SYNDROME

See: Ectodermal Dysplasias

ODONTOONYCHODERMAL DYSPLASIA

See: Ectodermal Dysplasias

ODONTOONYCHOHYPOHIDROTIC DYSPLASIA

See: Ectodermal Dysplasias

ODONTOTRICHODYSPLASIA WITH NEUTROPENIA

See: Ectodermal Dysplasias; Neutropenia

ODONTOTRICHOMELIC SYNDROME

See: Ectodermal Dysplasias

OLDFIELD SYNDROME

See: Colon Cancer, Hereditary; Polyposis

OLIGOPHRENIA-MICROPHTHALMOS

See: Norrie Disease

OLIGOSACCHARIDOSES

See: Tay-Sachs Disease

OLLIER DISEASE

See also: Growth Disorders

Ollier's/Maffuci Self-Help Group
c/o Bonnie Schmid-Hatch, founder
1824 Millwood Rd.
Sumter, SC 29150
(803) 775-1757
(803) 934-0347 (fax)
✉olliers@aol.com
http://www.ollier-maffucci.org
1,3,4,9

ONDINE'S CURSE

See: Central Hypoventilation Syndrome, Congenital

OPITZ FG SYNDROME

See: FG Syndrome

OPITZ HYPERTELORISM-HYPOSPADIUS SYNDROME

See: Opitz Syndrome

OPITZ OCULOGENITOLARYNGEAL SYNDROME

See: Opitz Syndrome

OPITZ SYNDROME

Opitz G/BBB Family Network
PO Box 516
Grand Lake, CO 80447
(970) 627-8935 (phone/fax)
(970)627-8818 fax
✉opitznet@mac.com
http://www.gle.egsd.k12.co.us/opitz/index.htm
1,2,3,4,5,6,7,8,9

OPITZ-BBBG COMPOUND SYNDROME

See: Opitz Syndrome

OPITZ-FRIAS SYNDROME

See: Opitz Syndrome

OPSOCLONUS-MYOCLONUS SYNDROME

See also: Myoclonus

Opsoclonus-Myoclonus Support Network
c/o Connie Quinn
725 North St.
Jim Thorpe, PA 18229
(717) 325-3302
✉clquinn@ptd.net
http://www.geocities.com/hotsprings/spa/2190
3

OPTIC NERVE HYPOPLASIA

See: Septo-Optic Dysplasia

ORBITAL HYPERTELORISM

See: Craniofacial Disorders

ORGANIC ACIDEMIA

See: Acidemia, Organic

ORNITHINE TRANSCARBAMYLASE (OTC) DEFICIENCY

See: Urea Cycle Disorders

OROFACIODIGITAL SYNDROME, TYPE I

See: Ectodermal Dysplasias

OSLER-WEBER-RENDU SYNDROME

See: Hemorrhagic Telangiectasis, Hereditary

OSTEITIS FIBROSA DISSEMINATA

See: McCune-Albright Syndrome

OSTEOCHONDROMATOSIS

See: Exostoses, Multiple Hereditary

OSTEOGENESIS IMPERFECTA

See also: Growth Disorders

Osteogenesis Imperfecta Foundation
804 W. Diamond Ave., Ste. 210
Gaithersburg, MD 20878
(800) 981-2663
(301) 947-0083
(301) 947-0456 (fax)
✉bonelink@oif.org
http://www.oif.org
1,2,3,4,5,6,7; *Support groups; Spanish materials*

OSTOMY

United Ostomy Association, Inc.
19722 MacArthur Blvd.,
Ste. 200
Irvine, CA 92612
(800) 826-0826
(949) 660-8624
(949) 660-9262 (fax)
✉uoa@deltanet.com
http://www.uoa.org
1,2,4,5,6,7; *National Conference in Reno, Nevada in July.*

United Ostomy Association of Canada, Inc
PO Box 46057
College Park PO
444 Yonge St.
Toronto, ON CAN M5B 2L8
(416) 595-5452
(416) 595-9924 (fax)
✉uoacan@astral.magic.ca
http://www3.ns.sympatico.ca/canada/ostomy
1,2,3,4,5,6,7,8,9; *youth network*

OXALOSIS & HYPEROXALURIA

See also: Kidney Disorders

Oxalosis & Hyperoxaluria Foundation
12 Pleasant St.
Maynard, MA 01754
(888)721-2432 PIN#5392
(978)461-0614
✉ohf@ohf.ultranet.com
http://www.ohf.org
1,2,8

OXOPROLINURIA

See: Acidemia, Organic

PACHYGYRIA

See: Lissencephaly

PACHYONYCHIA, CONGENITAL

See: Ectodermal Dysplasias

PAGON SYNDROME

See: Hydrocephalus; Lissencephaly

PALLISTER-HALL SYNDROME

See also: Anorectal Malformations; Pituitary Tumors

Pallister-Hall Foundation

Debra Messer
RFD Box 3000, Fairground Rd
Bradford, VT 05033
(802) 222-9683
✉messer@sover.net
http://www.kumc.edu/gec/support/palshall.html
2,3,4,9

PALLISTER-KILLIAN SYNDROME

See also: Epilepsy

Pallister-Killian Family Support Network
3700 Wyndale Ct.
Ft Worth, TX 76109
(817) 927-8854
(817) 927-2073 (fax)
3

PALMOPLANTAR HYPERKERATOSIS AND ALOPECIA

See: Ectodermal Dysplasias

PANCREATIC INSUFFICIENCY WITH NEUTROPENIA

See: Shwachman Syndrome

PANCYTOPENIA, CONGENITAL

See: Anemia, Fanconi

PANHYPOPITUITARISM

See: Growth Disorders

PANMYELOPATHY

See: Anemia, Aplastic

PANMYELOPHTHISIS

See: Anemia, Aplastic

PAPILLOMAS

See: Respiratory Papillomatosis, Recurrent

PAPILLON-LEFEVRE SYNDROME

See: Ectodermal Dysplasias

PARALYSIS, PERIODIC

See: Muscular Dystrophy

PARALYTIC POLIO

See: Polio

PARAMYOTONIA CONGENITA

See: Muscular Dystrophy

PARKES-WEBER SYNDROME

See: Klippel-Trenaunay Syndrome

PARRY-ROMBERG SYNDROME

See: Craniofacial Disorders

PATIN SYNDROME

See: Fibrodysplasis Ossificans Progressiva

PDD

See: Autism

PELIZAEUS-MERZBACHER DISEASE

See also: Leukodystrophy

The PMD Foundation
8100 Lincoln Dr. W., Suite D
Marlton, NJ 08053
(856) 396-0560
(856) 396-0451 (Fax)
✉mlaprocido@pmdfoundation.org
http://www.pmdfoundation.org

PEMPHIGUS, FAMILIAL

See: Ichthyosis

PEPCK DEFICIENCY

See: Lactic Acidosis; Mitochondrial Disorders

PERIPHERAL NEUROPATHY

See: Charcot-Marie-Tooth Disease

PERONEAL MUSCULAR ATROPHY

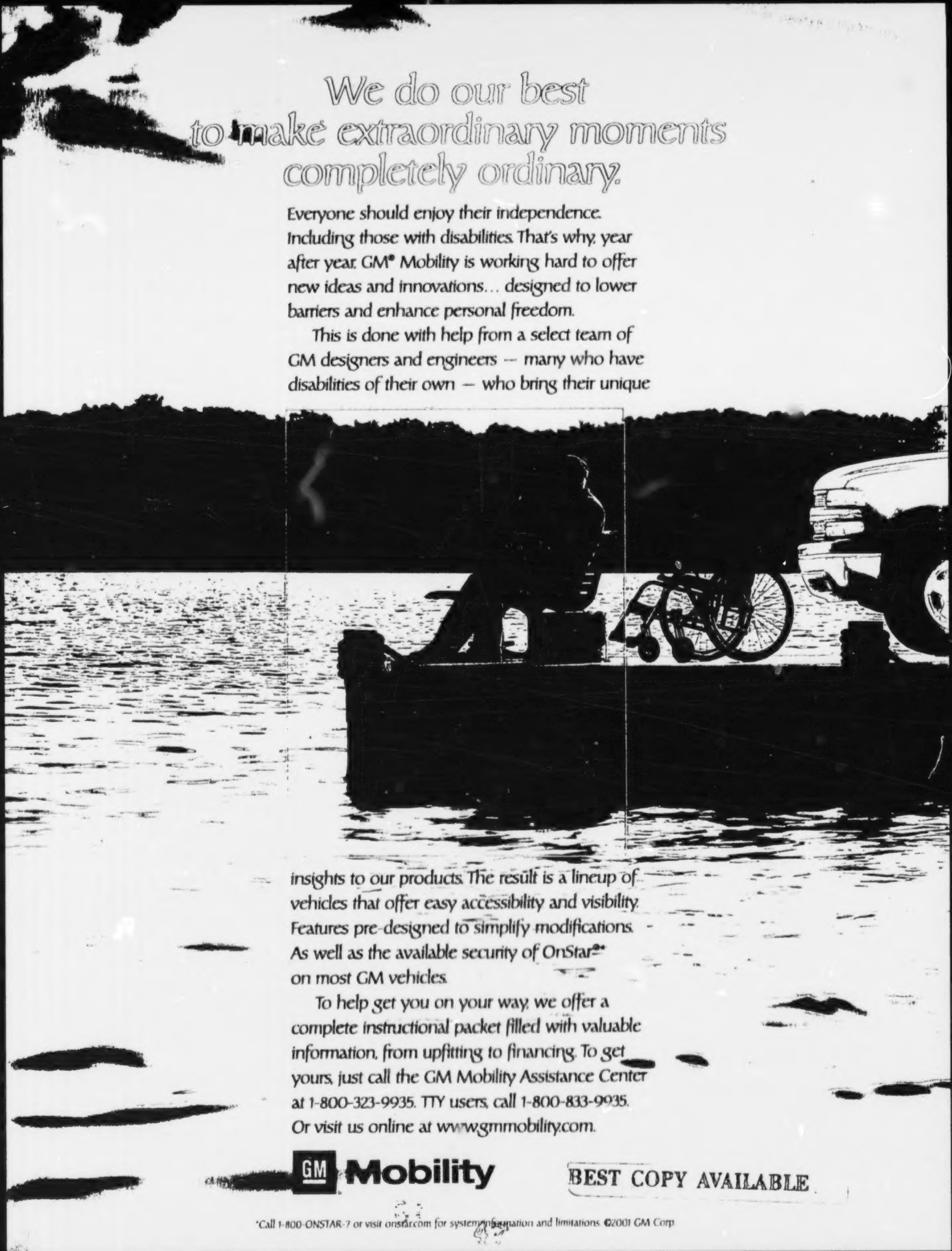
See: Charcot-Marie-Tooth Disease

PERVASIVE DEVELOPMENTAL DISORDER (PDD)

See: Autism

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry



We do our best to make extraordinary moments completely ordinary.

Everyone should enjoy their independence. Including those with disabilities. That's why, year after year, GM® Mobility is working hard to offer new ideas and innovations... designed to lower barriers and enhance personal freedom.

This is done with help from a select team of GM designers and engineers -- many who have disabilities of their own -- who bring their unique insights to our products. The result is a lineup of vehicles that offer easy accessibility and visibility. Features pre-designed to simplify modifications. As well as the available security of OnStar®* on most GM vehicles.

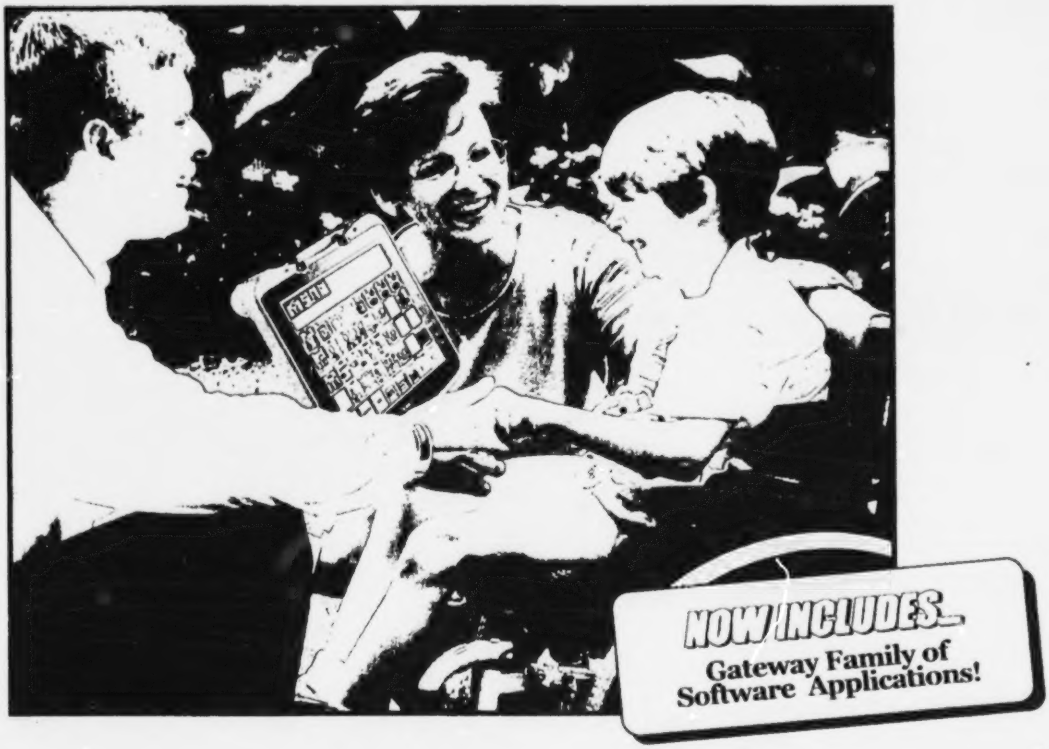
To help get you on your way, we offer a complete instructional packet filled with valuable information, from upfitting to financing. To get yours, just call the GM Mobility Assistance Center at 1-800-323-9935. TTY users, call 1-800-833-9935. Or visit us online at www.gmmobility.com.

GM Mobility

*Call 1-800-ONSTAR-7 or visit onstar.com for system information and limitations. ©2001 GM Corp.

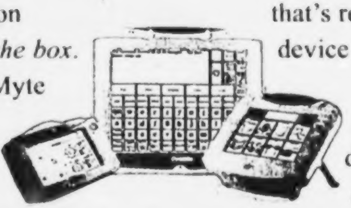
BEST COPY AVAILABLE

Communications for Life Just Got a Whole Lot Easier.



NOW INCLUDES...

Gateway Family of Software Applications!



Now even more DynaVox communication solutions are available to you right *out of the box*. When you order a new DynaVox or DynaMyte communication device, or DynaVox software from DynaVox Systems, you'll now receive ***Gateway to Language and Learning, Gateway 54*** and ***Gateway Junior, all developed by Joan Bruno, Ph.D., CCC-SLP*** *at no additional cost!* Plus, as an added convenience, we will install all three ***Gateway*** software programs on the device before it is shipped to you. More communicators will enjoy all the benefits of having a pre-designed vocabulary system that's ready to use as soon as their DynaVox device arrives.

DynaVox products have been helping people to communicate for nearly two decades. All of the professional associates at DynaVox are committed professionals dedicated to preserving dignity and pride...offering compassion and understanding...providing first quality communication products for the ones you love the most.

By making ***Gateway*** part of the DynaVox package, we're staying ***in touch*** with the kind of communication solutions that professionals want and our customers need.

DYNAVOX
a division of
SUNRISE MEDICAL

inTouch with Communication Solutions for Life.

For more information please contact our inside sales department at:

1-888-697-7332

www.dynavoxsys.com • e-mail: sales@dynavoxsys.com

Circle #54 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #134 or visit www.eparent.com/adinfo

no more frustration - just fun

LECKEY®

Advance Bath Chair

New Design

The most extensive height range and adjustable seat angles make bath positioning easy.

Extra-soft mesh material and padded support bars give your child a more comfortable and enjoyable bath time.

Take the Advance Bath Chair from the tub to the shower with the optional trolley

Also available is the Basic Bath Support that provides adjustable positioning angles at a fixed height.

And The FUN Doesn't Stop There

Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Call us today for more information.

- *Lighter mobile bases*
- *More adjustable components*
- *Peer level positioning*
- *Child friendly positioning straps*
- *Playful colors*

Pronestander

Freestander

Totstander

Toilet/Shower Chair

Easy Seat

SAMMONS® PRESTON
an AbilityOne

Leckey® products are brought to you exclusively by Sammons Preston®

Start the fun today! Contact your local Sammons Preston distributor or home health dealer for more information.

Or call Sammons Preston at

1-800-323-5547

Circle #114 or visit www.eparent.com/adinfo

ALLERGAN

Allergan, Inc., with headquarters in Irvine, California, is a technology-driven, global health care company that develops and commercializes specialty pharmaceutical products for the eye care, movement disorder, and dermatological markets as well as ophthalmic surgical devices and contact lens care solutions. In over 100 countries worldwide, **Allergan** markets products that deliver value to its customers, satisfy unmet medical needs and improve patients' lives.

Founded in 1948, **Allergan** has approximately 6,200 employees worldwide with 2000 sales of nearly $1.6 billion. **Allergan** is a pioneer in specialty pharmaceutical research, with a strong pipeline of products and technologies related to specific disease areas such as glaucoma, retinal disease, cataracts, dry eye, pain, movement disorders, and retinoid technology platforms with applications in psoriasis, acne, photodamage, metabolic disease, and various types of cancer. The Company has demonstrated its commitment to the Research and Development function by increasing its headcount nearly 30% during the last three years.

Circle #19 or visit www.eparent.com/adinfo

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

PEUTZ-TOURAINE SYNDROME
See: *Colon Cancer, Hereditary; Polyposis*

PFEIFFER SYNDROME
See: *Craniofacial Disorders*

PHAKOMATOSIS
See: *Tuberous Sclerosis*

PHENYLKETONURIA (PKU)
See also: Metabolic Disorders

Children's PKU Network
1520 State St., Ste. 111
San Diego, CA 92101
(619) 233-3202
(619) 233-0838 (fax)
✉pkunetwork@aol.com
2,4,7; *Spanish materials*

National Coalition
for PKU & Allied Disorders
P. O. Box 1244
Mansfield, MA 02048
(877)996-2723
http://www.pku-
allieddisorders.org

National PKU News
c/o Virginia Schuett
6869 Woodlawn Ave. NE,
Ste. 116
Seattle, WA 98115-5469
(206) 525-8140
(206) 525-5023 (fax)
✉schuett@pkunews.org
http://www.pkunews.org
1,3

PHOSPHOENOLPYRUVATE CARBOXYKINASE DEFICIENCY
See: *Lactic Acidosis; Mitochondrial Disorders*

PHOSPHOFRUCTO KINASE DEFICIENCY
See: *Glycogen Storage Diseases; Muscular Dystrophy*

PHOSPHOGLYCERATE KINASE DEFICIENCY
See: *Muscular Dystrophy*

PHOSPHOGLYCERATE MUTASE DEFICIENCY
See: *Muscular Dystrophy*

PHOSPHORYLASE B KINASE DEFICIENCY
See: *Glycogen Storage Diseases; Muscular Dystrophy*

PHOSPHORYLASE DEFICIENCY
See: *Glycogen Storage Diseases; Muscular Dystrophy*

PIERRE ROBIN SYNDROME
See: *Craniofacial Disorders; Growth Disorders*

PIGMENT DISORDERS
See: *Albinism & Hypopigmentation; Vitiligo*

PILI TORTI AND ENAMEL HYPOPLASIA
See: *Ectodermal Dysplasias*

PILI TORTI AND ONYCHODYSPLASIA
See: *Ectodermal Dysplasias*

PITUITARY DISORDERS/TUMORS

Pituitary Network Association
P.O Box 1958
Thousand Oaks,CA 91358
(805) 496-4932
(805) 557-1161 (fax)
✉pna@pituitary.org
http://www.pituitary.org
1,2,3,4,7,8

PITYRIASIS RUBRA PILARIS
See: *Ichthyosis*

POLIO

Informed Parents Against VAPP
(Vaccine Associated
Paralytic Polio)
PO Box 53212
Washington, DC 20009
(888) 363-8277
(703) 319-8277 (fax)
✉NOVAPP@aol.com
http://www.ipav.org
2,3,7,8,9

International Polio Network
4207 Lindell Blvd., #110
Saint Louis, MO 63108-2915
(314) 534-0475
(314) 534-5070 (fax)
✉gini_intl@msn.com
http://www.post-polio.org
1,2,4,6,8; *Local support groups.*

POLYCYSTIC KIDNEY DISEASE
See: *Kidney Disorders*

POLYENDOCRINE ADENOMATOSIS
See: *Multiple Endocrine Neoplasia I*

POLYMYOSITIS
See: *Muscular Dystrophy; Myositis*

POLYNEURITIS, ACUTE IDIOPATHIC
See: *Guillain-Barré Syndrome*

POLYNEUROPATHY, CHRONIC RELAPSING
See: *Guillain-Barré Syndrome*

POLYOSTOTIC FIBROUS DYSPLASIA
See: *McCune-Albright Syndrome*

POLYPOSIS
See also: Cancer; Colon Cancer, Hereditary

Familial Gastrointestinal
Cancer Registry
Mount Sinai Hospital
1157-660 University Ave.
Toronto, ON CAN M5G 1X5
(416) 586-8334
(416) 586-8644(fax)
✉tberk@mtsinai.on.ca
1,2,3,4,9; *French materials*

POLYRADICULONEUROPATHY
See: *Guillain-Barré Syndrome*

POMPE DISEASE
See also: Glycogen Storage Diseases; Muscular Dystrophy

The Children's Pompe Foundation
66 Witherspoon St, Ste 341
Princeton, NJ 08542
(609) 924-7192
(609) 767-2154 (fax)
http://www.pompe.org
✉info@pompe.org
2,3,4,7,8

PORPHYRIA

Metabolic Disorders American
Porphyria Foundation
PO Box 22712
Houston, TX 77227
(713) 266-9617
(713) 871-1788 (fax)
✉porphyrus@juno.com
http://www.enterprise.net/apf
1,2,3,4,8

Metabolic Disorders Canadian
Porphyria Foundation Inc.
Box 1206
Neepawa, MB CAN R0J 1H0
(204) 476-2800 (voice/fax)
✉porphyria@cpf-inc.ca
http://www.cpf-inc.ca
1,2;7,9; *French materials*

PORT WINE STAINS
See: *Sturge-Weber Syndrome*

POSTAXIAL ACROFACIAL DYSOSTOSIS
See: *Nager & Miller Syndromes*

PRADER-WILLI SYNDROME

Ontario Prader-Willi Syndrome
Association
1920 Yonge St. C104
Toronto, ON CAN M4S 3B2
(800) 563-1123
(416) 481-8657 (voice/fax)
✉prader willi@sympatico.ca
http://www3.sympatico.ca/prad
er-willi/
1,2,3,4,5,8,9; *French materials*

Prader-Willi Foundation
223 Main St.
Port Washington, NY 11050
(800) 253-7993
(516) 944-3173 (fax)
✉foundation@prader-
willi.inter.net
http://prader_willi.inter.net
2,3,4,7,8

The Prader-Willi Syndrome
Association (USA)
5700 Midnight Pass Rd., Ste. 6
Sarasota, FL 34242
(800) 926-4797
(941) 312-0400
(941) 312-0142 (fax)
✉pwsausa@aol.com
http://www.pwsausa.org
1,2,3,4,5,6,7,8,9; *English, Spanish and French materials*

PROGERIA

International Progeria Registry
c/o W. Ted Brown, MD, PhD
NY State Inst. for Basic Research
in Developmental Disabilities
1050 Forest Hill Rd.
Staten Island, NY 10314
(718) 494-5333
(718) 494-4835(fax)
✉wtbibr@aol.com
3,9

The Progeria Research
Foundation, Inc.
PO Box 3453
Peabody, MA 01961
(978) 535-2594
(978) 535-5849 (fax)
✉progeria@netzero.com
http://www.progeriare-
search.org
1,2,8,9

PROGRESSIVE HYPOERYTHEMIA
See: *Anemia, Aplastic*

PROGRESSIVE OSSEOUS HETEROPLASIA
See: *Connective Tissue Disorders; Fibrodysplasis Ossificans Progressiva*

PROPINONYL-COA CARBOXYLASE (PCC)
See: *Acidemia, Organic*

PROPIONIC ACIDEMIA
See: *Acidemia, Organic*

PROTEUS SYNDROME
See: *Neurofibromatosis*

PROTOCOPROPORPHYRIA
See: *Liver Disorders; Porphyria*

PROTOPORPHYRIA
See: *Liver Disorders; Porphyria*

PRUNE BELLY SYNDROME

Prune Belly Syndrome Network
100 UCLA Medical Plaza
Ste. 690
Los Angeles, CA 90095
(310) 825-6865
(310) 794-9962 (fax)
http://www.pedsuro.com
3,4

PSEUDO-HURLER POLYDYSTROPHY
See: *Mucopolysaccharidosis; Tay-Sachs Disease*

PSEUDOCHOLINESTERASE DEFICIENCY
See: *Malignant Hyperthermia*

PSEUDOXANTHOMA ELASTICUM (PXE)
See also: Connective Tissue Disorders; Heart Disorders; Macular Diseases; Visual Impairments

National Association for
Pseudoxanthoma Elasticum
3500 E. 12th Ave.
Denver, CO 80218-1910
(303) 355-3866
(303) 355-3859 (fax)
✉(at Texas Tech.)
derckd@ttuhsc.edu
✉(at Denver hdqtrs.)
pxenape@estreet.com
http://www.napxe.org
1,5,6; *newsletter provided on tape; low-vision clinic*

PSORIASIS

National Psoriasis Foundation
6600 SW 92nd Ave., Ste.300
Portland, OR 97222
(503) 244-7404
(800) 723-9166
(503) 245-0626 (fax)
✉getinfo@NPFUSA.org
http://www.psoriasis.org
1,2,3,4,6,7,8,9; *Spanish materials*

PTOSIS
See: *Blepharophimosis, Ptosis, Epicanthus Inversus Syndrome (BPES)*

PULMONARY VALVULAR STENOSIS
See: *Heart Disorders*

PURINE METABOLIC DISORDERS

Purine Research Society
5424 Beech Ave.
Bethesda, MD 20814-1730
(301) 530-0354
(301)564-9597 (fax)
✉purine@erols.com
http://www2.dgsys.com/~purine/
2,4,8

PURPURA HEMORRHAGICA
See: *Purpura, Idiopathic Thrombocytopenia (ITP)*

PURPURA, IDIOPATHIC THROMBOCYTOPENIA (ITP)

ITP Society
Children's Blood Foundation
333 E. 38th St. Rm. 830
New York, NY 10016-2745
(800) 487-7010 (ITP Hotline)
(212)297-4336 (office)
(212) 297-4340 (fax)
✉cbf@nyp.org
http://www.ultranet.com
/~itpsoc
2

PYRIMIDINE METABOLIC DISORDERS
See: *Purine Metabolic Disorders*

PYROGLUTAMICACIDURIA
See: *Acidemia, Organic*

PYRROLORPHYRIA
See: *Porphyria*

PYRUVATE CARBOXYLASE DEFICIENCY
See: *Acidemia, Organic; Lactic Acidosis*

PYRUVATE DEHYDROGENASE DEFICIENCY
See: *Acidemia, Organic; Lactic Acidosis*

PYRUVATE DEHYDROGENASE PHOSPHATASE
See: *Lactic Acidosis;*

Q-T PROLONGATION
See: *Long Q-T Syndrome*

RAPP-HODGKINS SYNDROME

See also: *Cleft Palate; Craniofacial Disorders; Deaf-Blind; Ectodermal Dysplasias; Hearing Impairments; Visual Impairments*

RASMUSSEN ENCEPHALITIS

See: *Rasmussen Syndrome*

RASMUSSEN SYNDROME

See also: *Epilepsy; Seizure Disorders*

Rasmussen Syndrome and Hemispherectomy Support Network
c/o Al and Lynn Miller
8235 Lethbridge Rd
Millersville, MD 21108
(410) 987-5221 (voice)
✉rssnlynn@aol.com
http://medhlp.netusa.net/
http://www/rasm.htm
http://www.familyvillage.wisc.edu/lib-rs.htm
1,2,3,6; *Spanish/ French/ Russian/Greek materials*

RECKLINGHAUSEN DISEASE

See: *Neurofibromatosis*

REFLEX SYMPATHETIC DYSTROPHY SYNDROME

Reflex Sympathetic Dystrophy Syndrome Association of America
116 Haddon Ave, Ste. D
Haddonfield, NJ 08033
(856) 795-8845 (voice/fax)
✉jwbroatch@aol.com
http://www.rsds.org
1,2,3,4,6,7,8

REFRACTORY ANEMIA

See: *Anemia, Aplastic*

REFSUM DISEASE

See: *Ichthyosis; Leukodystrophy; Tay-Sachs Disease*

RENAL DISORDERS

See: *Kidney Disorders*

RENDU-OSLER-WEBER SYNDROME

See: *Hemorrhagic Telangiectasis, Hereditary*

RESPIRATORY PAPILLOMATOSIS, RECURRENT

Recurrent Respiratory Papillomatosis Foundation
PO Box 6643
Lawrenceville, NJ 08648-0643
(609) 530-1443
(609) 530-1912 (fax)
✉rrpf@rrpf.org
www.rrpf.org
1,2,3,4,7,8,9

RETINITIS PIGMENTOSA

See also: *Macular Diseases; Usher Syndrome; Visual Impairments*

Retinitis Pigmentosa International
PO Box 900
Woodland Hills, CA 91364
(800) 344-4877
(818) 992-0500
(818) 992-3265 (fax)
✉RPINT@pacbell.net
http://www.rpinternational.org
1,2,4,7,8,9; *Spanish materials*

RP Research Foundation Fighting Blindness
c/o Sharon Cole or Margot Alward
60 St Claire Ave East St 703
Toronto, ON CAN M4T-1N5
(800) 461-3331 (Canada only)
(416) 360-4200
(416) 360-0060 (fax)
1,2,3,5,7,8; *French materials*

The Foundation Fighting Blindness
Mitsy Palmer, Constituent Services Coordinator &
Edy Asbell, Constituent Services Representative
11435 Cronhill Drive
Owings Mill, MD 211117-2220
(888) 394-3937
(800) 683-5551 (Toll Free TDD)
(410) 568-0150
(410) 363-7139 (local TDD)
(410) 363-2393 (fax)
✉info@blindness.org
http://www.blindness.org
1,2,3,4,5,6,8,9; *young adult program, retina donor program*

RETINOBLASTOMA

See: *Cancer; Visual Impairments*

National Retinoblastoma Parent Group
PO Box 317
Watertown, MA 02471
(800) 562-6265
(617) 972-7444 (fax)
1,2,3,4,5,7

RETINOCEREBRAL ANGIOMATOSIS

See: *Von Hippel-Lindau Syndrome*

RETT SYNDROME

International Rett Syndrome Association
9121 Piscataway Rd., Ste. 2B
Clinton, MD 20735
(800) 818-7388
(301) 856-3334
(301) 856-3336 (fax)
✉rettsyndromeontario@home.com
http://members.home.net/rettsyndromeontario
1,2,3,4,5,6,8;
Spanish/French/Russian/German materials

Ontario Rett Syndrome Association
147 Westdale Rd.
Oakville, ON CAN L6L 4Z7
(905) 844-7673
(905) 884-8730 (fax)
✉rettsyndromeontario@home.com
http://members.home.net/rettsyndromeontario
1,2,3,4,5,6,8

Rett Syndrome Research Foundation
4600 Devitt Dr.
Cincinnati, OH 45246
(513) 874-3020
(513) 874-2520 (fax)
http://www.rsrf.org
1,8,9

REYE SYNDROME

See: *Fatty Oxidation Disorder*

RILEY-DAY SYNDROME

See: *Familial Dysautonomia*

RING CHROMOSOME 15

See: *Chromosome Deletions; Craniofacial Disorders; Epilepsy; Heart Disorders; Kidney Disorders; Limb Disorders; Scoliosis*

RING CHROMOSOME 18

See: *Chromosome 13 & 18 Disorders; Chromosome 18 Disorders; Chromosome Deletions; Craniofacial Disorders; Deaf-Blind; Hearing Impairments; Visual Impairments*

RING CHROMOSOME 21

See: *Chromosome Deletions*

RING CHROMOSOME 22

See: *Chromosome Deletions*

RING CHROMOSOME 4

See: *Chromosome Deletions; Wolf-Hirschhorn Syndrome*

RING CHROMOSOME 9

See: *Chromosome Deletions; Craniofacial Disorders*

ROBINOW SYNDROME

See also: *Craniofacial Disorders; Short Stature*

Robinow Syndrome Foundation
c/o Karla M. Kruger
PO Box 1072
Anoka, MN 55303
(763) 434-1152
(763) 434-3691 (fax)
✉kmkruger@qwest.net
http://www.Robinow.org
1,3,6

ROBINSON SYNDROME

See: *Ectodermal Dysplasias*

ROMANO-WARD SYNDROME

See: *Long Q-T Syndrome*

ROSAI-DORFMAN DISEASE

See: *Histiocytosis*

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

ROSSELI-GULIENETTI SYNDROME

See: *Ectodermal Dysplasias*

ROTHMUND-THOMPSON'S SYNDROME

See: *Ectodermal Dysplasias*

RSH SYNDROME

See: *Smith-Lemli-Opitz Syndrome*

RUBINSTEIN SYNDROME

See: *Rubinstein-Taybi Syndrome*

RUBINSTEIN-TAYBI SYNDROME

See also: *Craniofacial Disorders; Heart Disorders*

Rubinstein-Taybi Parent Group
c/o Lorrie Baxter
PO Box 146
Smith Center, KS 66967
(888) 447-2989
(785) 697-2989
(785) 697-2985 (fax)
✉lbaxter@ruraltel.net
http://www.rubinstein-taybi.org
1,2,3,9

RUSSELL SYNDROME

See: *Russell-Silver Syndrome*

RUSSELL-SILVER SYNDROME

See also: *Growth Disorders; Short Stature*

The Magic Foundation Russell-Silver Support Group
1327 N. Harlem Ave.
Oak Park, IL 60302
(800) 3- Magic -3
(708) 383-0808
(708) 383-0899 (fax)
✉mary@magicfoundation.org
http://www.magicfoundation.org
2,3,4,5,6

SAETHRE-CHOTZEN SYNDROME

See: *Craniofacial Disorders*

SALAMON SYNDROME

See: *Ectodermal Dysplasias*

SANDHOFF DISEASE

See: *Tay-Sachs Disease*

SANFILIPPO SYNDROME

See: *Mucopolysaccharidosis; Tay-Sachs Disease*

SCHEIE SYNDROME

See: *Mucopolysaccharidosis; Tay-Sachs Disease*

SCHINZEL-GIEDION SYNDROME

See: *Apnea, Sleep; Deaf-Blind; Ectodermal Dysplasias; Epilepsy; Growth Disorders; Hearing Impairments; Visual Impairment*

SCID

See: *Immune Disorders*

SCLERODERMA

See also: *Arthritis; Autoimmune Disorders*

Scleroderma Federation
89 Newbury St., Ste. 201
Danvers, MA 01923
(800) 722-HOPE
(978) 750-4499
(978) 750-9902 (fax)
✉sfinfo@scleroderma.org
http://www.scleroderma.org
1,2,3,4,5,6,7,8,9

Scleroderma Research Foundation
PO Box 200
Columbus, NJ 08022
(800) 637-4005
(609) 723-7400
1,2,4

Scleroderma Foundation, Inc.
89 Newbury St.
Danvors, MA 01923
(800) 722-HOPE (4673)
(978) 750-4499
(978) 750-9902 (fax)
✉sfinfo@scleroderma.org
http://www.scleroderma.org
1,2,4,5,6,7,8,9

SCOLIOSIS

National Scoliosis Foundation
5 Cabot Pl.
Stoughton, MA 02072
(800) NSF-MYBACK (673-6922)
(781) 341-6333
(781) 341-8333 (fax)
✉nsf@scoliosis.org
http://www.scoliosis.org
1,2,3,4,5,6,7

SECKEL SYNDROME

See: *Craniofacial Disorders; Growth Disorders*

SEIZURE DISORDERS

See also: *Epilepsy*

THRESHOLD—Intractable Seizure Disorder Support Group & Newsletter
Epilepsy Foundation of New Jersey
Lion Head Office Park., Ste. 8A
35 Beaverson Blvd.
Brick, NJ 08733
(800) FSC-NJ10 (372-6510)
(732) 262-8020
(732) 262-4373 (fax)
✉fsnj@aol.com
http://www.efnj.com
1

SENSORY AND AUTONOMIC NEUROPATHY, HEREDITARY

See: *Familial Dysautonomia*

SENSORY MOTOR NEUROPATHY, HEREDITARY

See: *Charcot-Marie-Tooth Disease*

SENSORY NEUROPATHY WITH ANHIDROSIS, CONGENITAL

See: *Familial Dysautonomia*

SEPTO-OPTIC DYSPLASIA

See also: *Pituitary Tumors; Visual Impairments*

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

FOCUS: For Our Children's Unique Sight
4460 Fogg Ct.
San Diego, CA 92109
(858) 273-1473 (voice/fax)
✉support@focusfamilies.org
http://www.focusfamilies.org
1,2,3,9

SERUM PROTEASE INHIBITOR DEFICIENCY

See: *Alpha-1-Antitrypsin (AAT) Deficiency*

SEVERE COMBINED IMMUNODEFICIENCY (SCID)

See: *Immune Disorders*

SEX CHROMOSOME DISORDERS, FEMALE

See: *Turner Syndrome*

SEX CHROMOSOME DISORDERS, MALE

See: *Klinefelter Syndrome*

SHORT STATURE

See also: *Dwarfism; Growth Disorders*

Little People of America
PO Box 745
Lubbock, TX 79408
(806) 797-8830 (voice/fax; call first) Engl./Span.
(888)572-2001 (voice/fax; call first)
✉lpadatabase@juno.com
http://www.lpaonline.org
1,2,3,5,6; *Spanish materials*

SHPRINTZEN SYNDROME

See: *Velo-Cardio-Facial Syndrome*

SHWACHMAN SYNDROME

See also: *Growth Disorders*

Shwachman Diamond Syndrome, Intl.
c/o Nancy Ruick
5195 Hampsted Village Center Way,PMB # 162
New Albany OH, 43054-8331
1-877-SDS INTL(737-4685)
(614) 939-0752 (FAX)
✉4SSkids@shwachman-diamond.org
http://www.shwachman-diamond.org
1,2,3,4,6,8; *French/Italian/Dutch materials*

SHWACHMAN-DIAMOND SYNDROME

See: *Shwachman Syndrome*

SHY-DRAGER/MULTIPLE SYSTEM ATROPHIES

See also: *Dysautonomia*

Shy-Drager Syndrome MSA Support Group
2004 Howard Ln.
Austin, TX 78728
(866) 737-4999
(512) 251-3315 (fax)
http://www.shy-drager.com

SIALIDOSIS

See: *Mucopolysaccharidosis; Tay-Sachs Disease*

SIALOLIPIDOSIS

See: *Mucolipidosis Type IV*

SICKLE CELL ANEMIA

See: *Sickle Cell Disease*

SICKLE CELL DISEASE

Sickle Cell Disease Association of America
200 Corporate Pointe, Ste. 495
Culver City, CA 90203-8727
(800) 421-8453
(310) 216-6363
(310) 215-3722 (fax)
1,2,3,4,5,6,8,9

Sickle Cell Disease Association of the Piedmont
PO Box 20964
Greensboro, NC 27420
(800) 733-8297
(336) 274-1507
(336) 275-7984 (fax)
✉scdap@aol.com
http://www.greensboro.com/sickle/
1,2,3,4,5,6,7

SIDS

See: *Sudden Infant Death Syndrome (SIDS)*

SILVER SYNDROME

See: *Russell-Silver Syndrome*

SILVER-RUSSELL SYNDROME

See: *Russell-Silver Syndrome*

SIMPSON-GOLABI-BEHMEL SYNDROME

See: *Beckwith-Wiedermann Syndrome*

SKELETAL ANOMALIES

See: *Ectodermal Dysplasias*

SKELETAL DYSPLASIA

See: *Dwarfism; Growth Disorders; Short Stature*

SLEEP APNEA

See: *Apnea, Sleep*

SLO SYNDROME

See: *Smith-Lemli-Opitz Syndrome*

SLY SYNDROME

See: *Mucopolysaccharidosis; Tay-Sachs Disease*

SMITH-LEMLI-OPITZ SYNDROME

See: *Craniofacial Disorders*

Smith-Lemli-Opitz (RSH)
Advocacy & Exchange
2650 Valley Forge Drive
Boothwyn PA 19061
(610) 485-9663
(419) 781-3317 (fax)
✉bhook@erols.com
http://www.members.aol.com/slo97/index.html
1,2,3,6,9

SMITH-MAGENIS SYNDROME

PRISMS: Parents & Researchers Interested in Smith-Magenis Syndrome
76 So. New Boston Road
Francestown, NH 03043-3511
(603) 547-8384
(603) 547-3043 (fax)
✉info@smithmagenis.org
http://www.smithmagenis.org
1,2,3,4,5

SOTOS SYNDROME

See also: *Growth Disorders*

Sotos Syndrome USA Support Association
PMB #235
3 Danada Sq E.
Wheaton, IL 60187
(888) 246-SSSA
(630) 682-8815 (international)
✉sssa@well.com
http://www.well.com/user/sssa
1,2,3,4,6

SOUQUES-CHARCOT SYNDROME

See: *Progeria*

SOUTH AFRICAN GENETIC PORPHYRIA

See: *Liver Disorders; Porphyria*

SPASMODIC DYSPHONIA

See: *Dystonia*

SPASMODIC TORTICOLLIS

See: *Dystonia*

SPASMODIC WRYNECK

See: *Dystonia*

SPASTIC PARAPLEGIA, FAMILIAR

See: *Ataxia*

SPEECH DISORDERS

See: *Apraxia; Stuttering*

SPHINGOMYELIN LIPIDOSIS

See: *Niemann-Pick Disease*

SPIELMEYER-VOGT DISEASE

See: *Batten Disease*

SPIELMEYER-VOGT-BATTEN SYNDROME

See: *Batten Disease*

SPINA BIFIDA

See also: *Arnold-Chiari Malformation; Hydrocephalus; Incontinence; Latex Allergy*

Spina Bifida Association of America
4590 MacArthur Blvd. NW, Ste. 250
Washington, DC 20007-4226
(800) 621-3141
(202) 944-3285
(202) 944-3295 (fax)
✉sbaa@sbaa.org
http://www.sbaa.org
1,2,4,5,6,8; *Spanish materials, scholarship program*

Spina Bifida and Hydrocephalus Association of Canada
#167, 167 Lombard Ave.
Winnipeg, MB CAN R3B 0T6
(800) 565-9488 (Canada only)
(204) 925-3650
(204) 925-3654 (fax)
✉spinab@mts.net
http://www.sbhac.ca
1,2,4,5,6,7,8; *French materials*

SPINAL CORD INJURIES

See also: *Ventilator Use*

Christopher Reeve Paralysis Foundation
500 Morris Ave.
Springfield, NJ 07081
(800) 225-0292
(973) 379-2690
(973) 912-9433 (fax)
✉info@crpf.org
http://www.paralysis.org
1,8

National Spinal Cord Injury Association
8701 Georgia Ave., Ste. 500
Silver Spring, MD 20910-3723
(800) 962-9629 (hotline only)
(301) 588-6959
(301) 588-9414 (fax)
✉info@spinalcord.org
✉resource@spinalcord.org
http://www.spinalcord.org
1,2,4,5,6,7,8; *Spanish materials*

National Spinal Cord Injury Hotline
2200 Kernon Dr.
Baltimore, MD 21207
(800) 526-3456
(410) 448-6623 (local)
(410) 488-6627 (fax)
✉scihotline@aol.com
http://www.scihotlne.org
2,3,4,5

SPINAL MUSCULAR ATROPHY

Families of SMA
PO Box 196
Libertyville, IL 60048-0196
(800) 886-1762
(847) 367-7620
(847) 367-7623 (fax)
✉info@fsma.org
http://www.fsma.org
1,2,3,4,5,6,7,8,9; *Spanish materials*

SPINOCEREBELLAR ATAXIA

See: *Ataxia; Friedreich Ataxia*

SPLENIC ANEMIA, FAMILIAL

See: *Gaucher Disease*

SPONDYLOEPIPHYSEAL DYSPLASIA CONGENITA

See: *Cleft Palate; Growth Disorders; Visual Impairments*

SPONDYLOEPIPHYSEAL DYSPLASIA TARDA

See: *Growth Disorders*

SSPE

See: *Subacute Sclerosing Panencephalitis*

STAR PROTEIN DEFICIENCY

See: *Adrenal Disorders*

STARGARDT DISEASE

See: *Macular Diseases; Retinitis Pigmentosa; Visual Impairments*

STEELY HAIR DISEASE

Menkes Disease

STENGEL SYNDROME

See: *Batten Disease*

STENGEL-BATTEN-MAYOU-SPIELMEYER-VOGT DISEASE

See: *Batten Disease*

STICKLER SYNDROME

Stickler Involved People (SIP)
15 Angelina Dr.
Augusta, KS 67010
(316) 775-2993
http://www.stickler.org
✉sip@sticklers.org
1,2,3,6

STROKE

See also: *Aphasia, Acquired; Heart Disorders*

National Stroke Association
9707 E. Easter Ln.
Englewood, CO 80112-5112
(800) 787-6537
(303) 649-9299
(303) 649-1328(fax)
✉info@stroke.org
http://www.stroke.org
1,2,5,6,7,8; *Spanish/French materials*

Heart and Stroke Foundation of Canada
222 Queen St. Ste 1402
Ottawa, ON CAN K1P 5V9
(613) 569-4361
1-888-HSF-INFO (1-833-473-4636)
(613) 569-3278 (fax)
http://www.heartandstroke.ca
http://www.fmcoeur.ca
2 *(on Web or 888 phone),* ***4*** *(on 888 phone),* ***5,7,8***

STURGE-WEBER SYNDROME

See also: *Craniofacial Disorders; Epilepsy; Glaucoma; Klippel-Trenaunay Syndrome; Nevi, Giant Congenital; Neurofibromatosis; Tuberous Sclerosis; Von Hippel-Lindau Syndrome*

Sturge-Weber Foundation
PO Box 418
Mount Freedom, NJ 07970
(800) 627-5482
(927) 895-4445
(927) 895-4846 (fax)
✉swfoffice@aol.com
http://www.sturge-weber.com
1,2,3,4,6,7,8,9; *online support group*

Sturge-Weber Foundation (Canada) Inc
1960 Prairie Ave.
Port Coquitlam, BC CAN V3B 1V4
(604) 942-9209
(604) 942-6429 (fax)
✉kmoore@axionet.com
http://www.inforamp.net/~cvs0590
1,2,3,4,6,7,8,9

STUTTERING

National Center for Stuttering
200 East 33rd St.
New York, NY 10016
(800) 221-2483
(212) 683-1372 (fax)
✉executivedirector@stuttering.com
http://www.stuttering.com
2,4,5; *Spanish materials*

Speak Easy
c/o Mike Hughes
95 Evergreen Ave.
St John, NB CAN E2N 1H4
(506) 696-6799 (voice/fax)
(800) 345-9022(voice/fax)
✉info@speakeasycanada.com
http://www.speakeasycanada.com
1,2,4,5,6,7

Stuttering Foundation of America
PO Box 11749
Memphis, TN 38111-0749
(800) 992-9392
(901) 452-7343
(901) 452-3931 (fax)
✉stutter@vantek.net
http://www.stutteringhelp.org
2,4,6; *Spanish materials*

SUBACUTE NECROTIZING ENCEPHALOPATHY

See: *Mitochondrial Disorders*

SUBACUTE SCLEROSING PANENCEPHALITIS

See also: *Epilepsy; Visual Impairments*

National Subacute Sclerosing Panencephalitis Registry
c/o Paul Dyken, Director
Institute of Research in
Childhood Neurodegenerative
Diseases
PO Box 70191
Mobile, AL 36670-0191
(334) 478-6424
(334) 476-8277 (fax)
✉pdyken@aol.com
2,6,9

SUCCINYLCHOLINE SENSITIVITY

See: *Malignant Hyperthermia*

SUDDEN INFANT DEATH SYNDROME (SIDS)

Canadian Foundation for the Study of Infant Deaths
586 Eglinton Ave E., Ste. 308
Toronto, ON CA M4P 1P2
(800) 363-7437(Canada Only)
(416) 488-3260
(416) 488-3864 (fax)
✉sidsinfo@sidscanada.org
http://www.sidscanada.org/sids
1,2,3,4,5,6,7,8; *French/English materials*

National Sudden Infant Death Syndrome Resource Center
2070 Chain Bridge Rd., Ste. 450
Vienna, VA 22182
(703) 821-8955
(703) 821-2098 (fax)
✉sids@circsol.com
http://www.circsol.com/sids
1,2,4; *Spanish materials*

SUDECK ATROPHY

See: *Reflex Sympathetic Dystrophy Syndrome*

SULFATIDOSIS, JUVENILE, AUSTIN TYPE

See: *Hearing Impairments; Ichthyosis; Leukodystrophy; Tay-Sachs Disease*

SURDICARDIAC SYNDROME

See: *Hearing Impairments,Long Q-T Syndrome*

SWEDISH PORPHYRIA

See: *Porphyria*

SYNDACTYLIC OXYCEPHALY

See: *Apert Syndrome*

SYRINGOBULBIA

See: *Syringomyelia*

SYRINGOMYELIA

ASAP: American Syringomyelia Alliance Project
PO Box 1586
300 Green St. Ste. 206
Longview, TX 75606-1586
(800) 272-7282
(903) 236-7079
(903) 757-7456 (fax)
http://www.asap4sm.com

SYSTEMIC ELASTORRHEXIS OF TOURAINE

See: *Pseudoxanthoma Elasticum (PXE)*

SYSTEMIC MAST CELL DISEASE

See: *Mast Cell Disease, Systemic*

TANGIER DISEASE

See: *Tay-Sachs Disease*

TARGET CELL ANEMIA

See: *Cooley Anemia*

TARUI DISEASE

See: *Glycogen Storage Diseases; Muscular Dystrophy*

TAY SYNDROME

See: *Ichthyosis*

TAY-SACHS DISEASE

National Tay-Sachs and Allied Diseases Association
2001 Beacon St., Ste 204
Boston, MA O2135
(800) 90-NTSAD (68723)
(617) 277-4463
(617) 277-0134 (fax)
✉NTSAD-Boston@worldnet.att.net
http://www.ntsad.org
1,2,3,4,5,6,7,8; *Russian materials*

TEF (TRACHEOESOPHAGEAL FISTULA)

See: *VACTERL Association*

TESCHLER-NICOLA/KILLIAN SYNDROME

See: *Pallister Killian Syndrome*

THALASSEMIA MAJOR

See: *Cooley Anemia*

THROMBOCYTOPENIA ABSENT RADIUS (TAR) SYNDROME

See also: *Heart Disorders; Kidney Disorders; Short Stature*

Thrombocytopenia Absent Radius Syndrome Association
212 Sherwood Dr.
Egg Harbor Twp, NJ 08234-7658
(609) 927-0418
(609) 653-8639 (fax)
1,2,3,4,9

THYROID DISORDERS

See also: *Hypoparathyroidism*

Thyroid Foundation of America
Ruth Sleeper Hall
RSL 350 40 Parkman St
Boston, MA 02114-2698
(800) 832-8321
(617) 726-8500
(617) 726-4136 (fax)
✉info@tsh.org (for thyroid questions)
✉admin@tsh.org
http://www.tfaweb.org/pub/tfa
1,2,5,8

Thyroid Foundation of Canada
PO Box 1919
Station Main
Kingston, ON CAN K7L 5J7
(800) 267-8822
(613) 544-8364
(613) 544-9731 (fax)
✉thyroid@kos.net
http://www.thyroid.ca
1,2,3,7,8

TOOTH AND NAIL SYNDROME

See: *Ectodermal Dysplasias*

TORSION DYSTONIA, IDIOPATHIC

See: *Dystonia*

TOURETTE SYNDROME

See also: *Attention Deficit Disorder; Obsessive-Compulsive Disorder*

Tourette Syndrome Association
42-40 Bell Blvd.
Bayside, NY 11361-2820
(718) 224-2999
(718) 279-9596 (fax)
✉ts@tsa-usa.org
http://www.tsa-usa.org
1,2,4,5,6,7,8,9; *Spanish materials*

Tourette Syndrome Foundation of Canada
194 Jarvis St., Ste. 206
Toronto, ON CAN M5B 2B7
(800) 361-3120 (Canada only)
(416) 861-8398
(416) 861-2472 (fax)
✉ tsfc.org@sympatico.ca
http://www.tourette.ca
1,2,3,4,5,6,7,8; *to a very small degree.; school in- servicing program; print material in French and English.; kids' programs*

TOXIC PARALYTIC ANEMIA

See: *Anemia, Aplastic*

TREACHER COLLINS SYNDROME

See also: *Craniofacial Disorders; Hearing Impairments*

Treacher Collins Foundation
PO Box 683
Norwich, VT 05055-0683
(800) 823-2055
(802) 649-3050
http://www.treachercollinsfnd.org
1,2,3,4,6

TREMOR

International Tremor Foundation
7046 W 105th St.
Overland Park, KS 66212-1803
(888) 387-3667 (toll free)
(913) 341-3880
(913) 341-1296 (fax)
✉staff@essentialtremor.org
http://www.essentialtremor.org
1,2,3,4,5,7,8,9

TRICHODENTOOSSEOUS SYNDROME; TYPES I, II & III

See: *Ectodermal Dysplasias*

TRICHODYSPLASIA-ONYCHOGRYPOSIS-HYPOHIDROSIS-CATARACT

See: *Ectodermal Dysplasias*

TRICHOFACIOHYPOHIDROTIC SYNDROME

See: *Ectodermal Dysplasias*

TRICHONYCHODENTAL DYSPLASIA

See: *Ectodermal Dysplasias*

TRICHONYCHODYSPLASIA WITH XERODERMA

See: *Ectodermal Dysplasias*

TRICHOOCULODERMOVERTEBRAL SYNDROME

See: *Ectodermal Dysplasias*

TRICHOODONTOONYCHIAL DYSPLASIA

See: *Ectodermal Dysplasias*

TRICHOODONTOONYCHO-HYPOHIDROTIC DYSPLASIA WITH CATARACT

See: *Ectodermal Dysplasias*

TRICHOODONTOONYCHODERMAL SYNDROME

See: *Ectodermal Dysplasias*

TRICHOODONTOONYCHODYSPLASIA WITH PILI TORTI

See: *Ectodermal Dysplasias*

TRICHOPOLIODYSTROPHY

See: *Menkes Disease*

TRICHORHINOPHALANGEAL (TRP) SYNDROME

See: *Ectodermal Dysplasias*

TRICHOTILLOMANIA

See: *Obsessive-Compulsive Disorder*

TRIPHALANGEAL THUMBS-ONYCHODYSTROPHY-DEAFNESS

See: *Ectodermal Dysplasias; Hearing Impairments*

TRP SYNDROME, TYPE I

See: *Ectodermal Dysplasias*

TRPS SYNDROME, TYPE II

See: *Ectodermal Dysplasias*

TUBEROUS SCLEROSIS

See also: *Autism; Epilepsy; Learning Disabilities*

Tuberous Sclerosis Alliance
801 Roeder Road # 750
Silver Spring, MD 20910
(800) 225-6872
(301) 562-9890
(301) 562-9870 (fax)
✉tsalliance@tsalliance.org
http://www.tsalliance.org
1,2,3,6,8; *national volunteer support network*

Tuberous Sclerosis Canada Sclérose Tubéreuse
2443 New Wood Dr.
Oakville, ON CAN L6H 5Y3
(800) 347-0252
(905) 257-1997
(905) 257-4778 (fax)
✉1nfo@tscst.org
http://www.tscst.org
1,2,3,4,7,8

TURCOT SYNDROME

See: *Brain Tumors; Cancer Hereditary Colon Cancer*

TURNER SYNDROME

See also: *Growth Disorders*

Turner Syndrome Society of Canada
814 Glencairn Ave
Toronto, ON CAN M6B 2A3
(800) 465-6744
(416) 781-2086
(416) 781-7245 (fax)
✉tssincan@web.net
http://www.turnersyndrome.ca
1,2,3,4,5,6; *French Materials*

Turner Syndrome Society of the US
14450 TC Jester, Ste. 260
Houston, TX 77014
(800) 365-9944
(832) 249-9988
(612) 249-9987 (fax)
✉shel@turner-syndrome-us.org
http://www.turner-syndrome-us.org
1,2,3,4,5,6,9; *Spanish materials*

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES

TWIN-RELATED DISEASES

Conjoined Twins International
PO Box 10895
Prescott, AZ 86304-0895
✉dwdegeraty@excelonline com
1,2,3,4,8,9

Twin Hope
2592 West 14th St
Cleveland, OH 44113
(216) 687-2544
✉twinhope@twinhope com
http //www.twinhope.com
1,2,3,4,5,7,8,9; materials available in Spanish, German, and French: family guides

TWIN TO TWIN TRANSFUSION SYNDROME

See also: *Twin-Related Diseases*

Twin to Twin Transfusion Syndrome Foundation
411 Longbeach Parkway
Bay Village, OH 44140
(440) 899-8887
(440) 899-1184 (fax)
✉info@tttsfoundation.org
http //www.tttsfoundation.org
1,2,3,4,5,7,8,9

TYROSINEMIA, HEREDITARY, HEPATORENAL TYPE/ TYROSINEMIA TYPE I, TYROSYLURIA

See also: *Kidney Disorders; Liver Disorders*

Groupe Aide aux Enfants Tyrosinemiques du Quebec
3162 Rue Granville
Jonquiere, QC CAN G7S 2B9
(418) 548-1580
✉gerard tremblay@sympatico.ca
http //www members xoom.co m/Tyrosine/tyrosine html
2,4,8,9; *English/French materials; support available in Spanish*

ULCERATIVE COLITIS

See: *Crohn Disease & Colitis*

UREA CYCLE DISORDERS

See also: *Metabolic Disorders*

National Urea Cycle Disorders Foundation
4841 Hill St
La Canada, CA 91011
(800) 386-8233
✉info@nucdf org
http //www.nucdf org
1,2,3,4,6,7,8,9

UROLOGIC DISORDERS

See: *Incontinence; Kidney Diseases, Hereditary; Kidney Disorders*

UROSTOMY

See: *Ostomy*

URTICARIA PIGMENTOSA

See: *Mast Cell Diseases*

USHER SYNDROME

See also: *Deaf-Blind; Hearing Impairments; Retinitis Pigmentosa; Visual Impairments*

Usher Around The World
c/o Kathie Anderson
PO Box 17318
Minneapolis, MN 55417
(612) 729-4630 (voice/TDD)
(612) 724-6982 (fax)
1,3

VACTERL ASSOCIATION

See also: *Anorectal Malformations; CHARGE Association; Heart Disorders; Kidney Disorders; Limb Disorders, Spina Bifida*

TEF/VATER International Support Network
c/o Greg and Terri Burke
15301 Grey Fox Rd.
Upper Marlboro, MD 20772
(301) 952-6837
(301) 952-9152 (fax)
✉tefvater@ix netcom.com
http //www tefvater org
1,2,3,7,8,9

VAN MEERKEREN I SYNDROME

See: *Ehlers-Danlos Syndrome*

VASCULAR MALFORMATIONS

See: *Klippel Trenaunay Syndrome; Sturge-Weber Syndrome; Von Hippel-Lindau Syndrome*

VATER ASSOCIATION

See: *VACTERL Association*

VELO-CARDIO-FACIAL SYNDROME

See also: *CHARGE Association; Craniofacial Disorders; Heart Disorders*

Northeast VCFS Support Group
2 Lansing Dr.
Salem, NH 03079
(603) 898-6332
✉MLADJA@aol.com
1,2,3,6,9;
international educational foundation for research

Velo-Cardio-Facial Syndrome Educational Foundation, Inc.
Upstate Medical University
University Hospital
708 Jacobsen Hall (C.D.U.)
750 E. Adams St.
Syracuse, NY 13210
(315) 464-6590
(315) 464-6593
✉vcfsef@mail upstate edu
http //www.vcfs.org
2,3,4,9

VENTILATOR USE

Citizens for Independence in Living & Breathing
78 Golfwood Heights
Toronto, ON CAN M9P 3M2
(416) 244-2248 (phone/fax)
2,3,4,6,7,9

International Ventilator Users Network
(IVUN)
4207 Lindell Blvd., #110
St Louis, MO 63108-2915
(314) 534-0475
(314) 534-5070 (fax)
http //www.post-polio.org/index html
1,2,3,4,6,7,8

VENTRICULAR DEFECTS

See: *Heart Disorders*

VERMIS CEREBELLAR AGENESIS

See: *Joubert Syndrome*

VESTIBULAR DISORDERS

See also: *Balance Disorders & Dizziness*

Vestibular Disorders Association
PO Box 4467
Portland, OR 97208-4467
(800) 837-8428
(503) 229-8064 (fax)
✉veda@vestibular.org
http //www.vestibular.org
1,2,3,4; *Spanish Materials*

VISUAL IMPAIRMENT/ HEARING IMPAIRMENT

See: *Deaf-Blind*

VISUAL IMPAIRMENTS

See also: *Albinism & Hypopigmentation; Glaucoma; Macular Diseases; Retinitis Pigmentosa; Retinoblastoma; Septo-Optic Dysplasia; Usher Syndrome*

American Council of the Blind
1155 15th St NW, Ste.1004
Washington, DC 20005
(800) 424-8666
(202) 467-5081
(202) 467-5085 (fax)
✉info@acb org
http //www.acb.org
1,2,4,5,6

American Foundation for the Blind
11 Penn Plaza, Ste. 300
New York, NY 10001
(800) 232-5463
(212) 502-7600
(212) 502-7662 (TDD)
✉afbinfo@afb.org
http://www.afb.org
1,2,4,5,6,8

Blind Children's Center
4120 Marathon St.
Los Angeles, CA 90029
(800) 222-3566
(800) 222-3567 (CA only)
(323) 664-2153
(323) 665-3828 (fax)
✉info@blindchildrenscenter.org
http //www blindchildrenscenter. org
1,2,3,4,8; *Spanish materials*

Blind Children's Fund
4740 Okemos Rd.
Okemos, MI 48864
(517) 347-1357
(517) 347-1459 (fax)
✉blindchfnd@aol. com
http //www blindchildrensfund. org
1,2,4,6

Blind Children's Fund Resource Center
2971 53rd St. SE
Auburn, WA 98092
(206) 735-6350 (voice/fax)
✉blindchildrensfund@charitiesusa.com
1,2,4,6

Braille Institute of America
741 N. Vermont Ave.
Los Angeles, CA 90029
(323) 663-1111
(323) 663-0867 (fax)
✉info@brailleinstitute.org
http //www brailleinstitute.org

Canadian National Institute for the Blind
1929 Bayview Ave.
Toronto, ON CAN M4G 3E8
(416) 486-2500
(416) 480-7417 (TDD)
(416) 480-7699 (fax)
✉marjerb@east cnib.ca
http //www.cnib ca
1,2,3,4,6,7,8; French materials

Council of Families with Vision Impairment
6212 W. Franklin St.
Richmond, VA 23226
(804) 288-0395
1,2,3,4,6,7

The Foundation for Fighting Blindness
11435 Cranhill Drive
Owings Mill, MD, 21117-2220
(800) 683-5555 (TDD)
(410) 363-7139 (local TDD)
(410) 363-2393 (FAX)
✉Mpalmer@blindness.org
http //www blindness.org

The Lighthouse National Center for Vision and Child Development
111 East 59th St.
New York, NY 10022
(800) 334-5497(voice)
(212) 821-9200 (voice)
(212) 821-9713 (TDD)
(212) 821-9705 (fax)
✉mbeck@lighthouse org
http //www lighthouse org
1,2,4; *Spanish materials*

National Association for Parents of Children with Visual Impairments
PO Box 317
Watertown, MA 02471
(800) 562-6265
(617) 972-7441
(617) 972-7444 (fax)
✉napvi@perkins pvt k12 ma us
http //www spedex.com/napvi
1,2,3,5,6,7; *Spanish materials*

National Association for Visually Handicapped
22 W 21st St., 6th Fl.
New York, NY 10010
(212) 889-3141
(212) 727-2931 (fax)
✉staff@navh.org
http //www.navh org
1,2,4,7; *Spanish/Russian Mandarin materials; large-print lending library*

National Braille Press
88 St. Stephen St.
Boston, MA 02115
(800) 548-7323
(617) 266-6160
(617) 437-0456 (fax)
✉orders@nbp org
http //www.npb org
1,2,7

National Organization of Parents of Blind Children
National Center for the Blind
1800 Johnson St.
Baltimore, MD 21230
(410) 659-9314 x360
(410) 685-5653 (fax)
✉bcheadle@nfb org
http //www.nfb.org
1,2,3,4,5,6,7; *Spanish materials.*

Prevent Blindness America
500 E Remington Rd
Schaumburg, IL 60173-4557
(800) 331-2020
(847) 843-2020
(847) 843-8458 (fax)
✉74777 100@compuserve.com
http //www prevent blindness. org
1,2,4,5,6,7,8; *Spanish materials*

Recording for the Blind & Dyslexic
20 Roszel Rd.
Princeton, NJ 08540
(609) 520-8079
(609) 520-7990 (fax)
✉info2rfbd org
http //www.rfbd.org
2

Vision World Wide, Inc.
5707 Brockton Dr., Ste. 302
Indianapolis, IN 46220-5481
(800) 431-1739
(317) 254-1332
(317) 251-6588 (fax)
✉info@visionww.org
http //www visionww org
1,2,4,

VITAMIN B12 METABOLISM; INBORN ERROR OF

See: *Cobalamin (B12) Defiency*

VITILIGO

The Canadian Vitiligo Society
Dr. Danuta Pawlowski
University Health Network
Toronto Western Hospital
8th Fl., Rm. 542
399 Bathurst St
Toronto, Ontario CAN M5T 2S8
(416) 603-5721
(416) 603-2782 (fax)

National Vitiligo Foundation
611 South Fleishel Ave
Tyler, TX 75701
(903) 531-0074
(903) 525-1234 (fax)
✉vitiligo@trimofran.org
http //www.vitiligofoundation.org
1,2,3,4,5,6,7,8,9

VON GIERKE DISEASE

See: *Glycogen Storage Diseases*

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

VON HIPPEL-LINDAU SYNDROME

See also: Ataxia; Balance Disorders & Dizziness; Brain Tumors; Visual Impairments

Von Hippel-Lindau Syndrome Family Alliance
171 Clinton Rd
Brookline, MA 02445-5815
(800) 767-4845
(617) 277-5667
(617) 734-8233 (fax)
✉info@vhl.org
http://www.vhl.org
1,2,3,4,5,7,8,9; *Spanish/French/German/ Dutch/Italian materials.*

VON RECKLINGHAUSEN DISEASE

See: Neurofibromatosis

VON WILLEBRAND DISEASE

See: Hemophilia

VROLIK DISEASE, TYPE II

See: Osteogenesis Imperfecta

WAGR SYNDROME

See also: Aniridia; Wilm's Tumor

The WAGR Network
c/oAnnie Prusakiewicz
2063 Regina Ave
Lincoln Park, MI 48146
(313) 381-4302
✉ReachingOutNet@aol.com
http://www.wagr.org
http://members.aol.com/ReachingOutNet/index.htm
1,2,3,8,9

WALBAUM-DEHEANE-SCHLEMMER SYNDROME

See: Ectodermal Dysplasias

WALKER-WARBURG SYNDROME

See: Hydrocephalus; Lissencephaly

WARBURG SYNDROME

See: Hydrocephalus; Lissencephaly

WEBER SYNDROME

See: Sturge-Weber Syndrome

WEGENER GRANULOMATOSIS

See also: Immune Disorders

Wegener's Granulomatosis Association (International)
PO Box 28660
Kansas City, MO 64188-8660
(800) 277-9474
(816) 436-8211(fax)
✉wgsg@wgsg.org
http://www.wgassociation.org
1,2,3,4,5,6; *international conferences*

WERDNIG-HOFFMAN DISEASE

See: Spinal Muscular Atrophy

WERLHOF DISEASE

See: Purpura, Idiopathic Thrombocytopenia (ITP)

WERMER SYNDROME

See: Multiple Endocrine Neoplasia I

WERNER SYNDROME

See: Progeria

WHISTLING FACE SYNDROME

See: Freeman-Sheldon Syndrome

WHISTLING FACE-WINDMILL VEIN HAND SYNDROME

See: Freeman-Sheldon Syndrome

WHITE MATTER DISORDERS

See: Leukodystrophy

WHITE SPOT DISEASE

See: Vitiligo

WHITNALL-NORMAN SYNDROME

See: Norrie Disease

WILLIAMS SYNDROME

See also: Autism; Attention Deficit Disorder; Growth Disorders; Heart Disorders; Learning Disabilities; Noonan Syndrome

Williams Syndrome Association
PO Box 297
Clawson, MI 48017-0297
(248) 541-3630
(248) 541-3631 (fax)
✉wsaoffice@aol.com
http://www.williams-syndrome.org
1,2,3,4,5,6,8; *DNA research bank, annual music camp*

WILLIAMS-BEUREN SYNDROME

See: Williams Syndrome

WILM'S TUMOR

See: WAGR Syndrome, Genitalia, Ambiguous

WILSON'S DISEASE

Wilson's Disease Association
4 Navaho Dr.
Brookfield, CT 06804-3124
(800) 399-0266
(203) 775-9666
✉haseltner@worldnet.att.net
http://www.wilsonsdisease.org
1,2,7,8

WISKOTT-ALDRICH SYNDROME

See: Immune Disorders; Purpura, Idiopathic Thrombocytopenia

WOLF SYNDROME

See: Wolf-Hirschhorn Syndrome

WOLF-HIRSCHHORN SYNDROME

See also: Chromosome 4p

4p- Parent Network
C/o Bonnie Radtke
1874 NW 108 Ave
Plantation, FL, 33322
(954) 476-9345
✉bbr@juno.com
http://members.aol.com/lbent503/whs
1,2,3,6,9

X-LINKED ALPHA THALASSEMIA

See: Alpha Thalassemia Mental Retardation Syndrome, X-linked

X-LINKED COPPER DEFICIENCY

See: Menkes Disease

X-LINKED COPPER MALABSORPTION

See: Menkes Disease

X-LINKED MYOTUBULAR MYOPATHY

See: Myotubular Myopathy, X Linked; Muscular Dystrophy

XANTHOGRANULOMATOSIS, JUVENILE

See: Histiocytosis

XERODERMA PIGMENTOSUM

Canadian Organization of Rare Disorders (CORD)
PO Box 814
Coaldale, AB CAN T1M 1M7
(877) 702-7273
(403) 345-4544
(403) 345-3948 (fax)
office@cord.ca
http://www.cord.ca
1,2,3,4

XP Society
PO Box 4759
Poughkeepsie, NY 12602
(518) 851-2612 (phone/fax)
http://www.xps.or

XERODERMA-TALIPES-ENAMEL DEFECT

See: Ectodermal Dysplasias

ZANIER-ROUBICEK SYNDROME

See: Ectodermal Dysplasias

ZELLWEGER SYNDROME

See: Leukodystrophy

ZIEHEN-OPPENHEIM DISEASE

See: Dystonia

Matching Resources

This directory of "Matching Resources"—both national and international—can help some parents who have children with extremely rare conditions or unique combinations of disabilities. Others may be dealing with unique family situations, such as single parenting, raising twins, or adoption. These networking organizations do parent-to-parent matching based on children's disabilities and, in some cases, other unique family situations. Most maintain ongoing contact with other groups worldwide.

Unless otherwise noted, all services are provided free of charge. This symbol, ✉, indicates an e-mail address. All international calls from the US or Canada require dialing 011 before the number. Please be aware of time zone differences when making any calls, particularly international ones. (Unless otherwise noted, telephone numbers are for voice only.)

Birth Defect Research for Children
930 Woodcock Rd., Ste. 225
Orlando, FL 32803
(407) 895-0802
(407) 895-0824 (fax)
http://www.birthdefects.org
✉abdc@birthdefects.org
1,2,3,4,5,9

Canadian Organization for Rare Disorders (CORD)
PO Box 814
Coaldale, AB CAN T1M 1M7
(877) 302-7273
(403) 345-4544
(403) 345-3948 (fax)
✉office@cord.ca
http://www. cord.ca
1,2,3,4

Easter Seals
National Headquarters
230 West Monroe St., Ste. 1800
Chicago, IL 60606
(800) 221-6827
(312) 726-6200 (voice)
(312) 726-4258 (TDD)
(312) 726-1494 (fax)
✉info@easter-seals.org
http://www.easter-seals.org
1,2,4,5,8; *Early Intervention Services; Physical, Occupational, Speech Therapies; Job Training & Employment; Inclusive Child Care; Adult Day Services, Camping & Recreation*

Easter Seals Society
1185 Eglinton Ave E.St 706
North York ,
ON CAN M3C-3C6
(416) 421-8377
(416) 696-1035 (fax)
✉info@easterseals.org
http://www.easterseals.org
1,4,5,8; *Financial Assistance, Camping*

MUMS Mothers United for Moral Support
c/o Julie Gordon
150 Custer Ct
Green Bay, WI 54301-1243
(920) 336-5333
(877) 336-5333 (Parents only please)
(920) 339-0995 (fax)
✉mums@netnet.net
http://www.netnet.net/mums/
1,3,4

National Organization for Rare Disorders (NORD).
100 Rt. 37, PO Box 8923
New Fairfield, CT 06812-8923
(800) 999-6673
(203) 746-6518
(203) 746-6481 (fax)
✉orphan@rarediseases.org
http://www.rarediseases.org
1,3,4,6,7,8

OTHER RESOURCES

Search & Respond
c/o Exceptional Parent Magazine
65 East Route 4
River Edge, NJ. 07661
(201) 489-0633 (fax)
✉epedit@aol.com
http://www.eparent.com
Parents, professionals, and other searching for information, networking, or advice on a disability or related problem may send correspondence to Exceptional Parent's Search & Respond column in the magazine and/or on the Web site: http://www.eparent.com. Some letters are selected for publication in the monthly column. Anyone offering a suggestion may write a "Respond" letter, which will be forwarded and may also be published.

PARENT TO PARENT PROGRAMS

Parent to Parent (P-P) programs provide informational and emotional support to parents who have a child, adolescent, or adult family member with special needs. P-P programs offer an important connection for a parent who is seeking support for a disability-related issue by matching him or her with a trained "veteran" parent who has already "been there." Because the two parents share so many common concerns and interests, the support given and received is often uniquely meaningful. The Parent to Parent match between two parents who both have family members with special needs provides support that is different from that provided in support groups or by professionals.

P-P programs have been providing one-to-one matches for more than 25 years. The major components are screening and training of veteran parents, careful matches based on similar family and disability issues, and follow-up support for each match. Many P-P programs also offer a range of other activities including parent groups for education and support, social events, resource libraries, and services for other family members. Some states have a statewide P-P program that offers training and technical assistance to local programs. These statewide P-P programs often have extensive computerized databases that allow them to make a statewide match when an appropriate local match cannot be found.

INTERNATIONAL PARENT TO PARENT CONFERENCE

Every other year, parents, P-P program directors, and other professionals in the families and disability field, gather at the International Parent to Parent Conference. The Eleventh International Parent to Parent Conference will be held in Philadelphia, Pennsylvania, April 4-7, 2002. For further information, please contact: Parent to Parent of Pennsylvania at (717) 540-4722, or visit http://www.parenttoparent.org.

USING THIS DIRECTORY

This directory contains P-P programs that gave Exceptional Parent magazine permission for contact information to be included in the Exceptional Parent Resource Guide and that provided at least both an address and a telephone number. (Unless indicated, all telephone numbers are for voice only.) **Statewide P-P programs have an asterisk (*) by their names,** and local programs that are affiliated with the Statewide program are not listed separately for local programs in the state. If you are looking for a local program in a state that has a statewide program, please contact the statewide program for contact information. When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the symbol ✉. Web sites are listed with the standard http:// before each.

If you do not find a local program in your community, or if you wish to add or make revisions to this list, please contact the Beach Center on Disability, 3136 Haworth Hall, University of Kansas, 1200 Sunnyside Avenue, Lawrence, KS 66045; telephone: (785) 864-7600 (voice/TDD); fax: (785) 864-7605.

ALABAMA

Friends for Life
Auburn United Methodist Church
137 S. Gay St.
Auburn, AL 36830
(334) 826-8800
Special Education Action
Committee
Birmingham Outreach Office
25 W. Oxmoor Rd., Ste. 50
Birmingham, AL 35209
(205) 941-0313 (voice/TDD)
(256) 941-0987 (fax)

The Arc of Morgan County
401 14th St. SE, Ste. 4-E
Decatur, AL 35601
(205) 355-6192
(256) 350-4502 (fax)
✉arc@hiwaay.net

Parent Connection Network of Alabama
PO Drawer 1627
Dothan, AL 36302-1627
(800) 846-3697
(800) 677-9123 (AL only)
(334) 792-0022
(334) 702-8442 (fax)

SEAC Parent Assistance Center
Huntsville Outreach Office
3322 S. Memorial Pkwy., Ste. 238
Huntsville, AL 35801
(800) 222-7322 (AL only)
(256) 882-3911 (office)
(256) 882-3974 (fax)
✉seachsv@hiwaay.net
http://home.hiwaay.net/~seachsv
1,2,4

***Special Education Action Committee**
PO Box 161274
Mobile, AL 36616-2274
(800) 222-7322 (AL only)
(251) 478-1208 (voice/TDD)
(251) 473-7877 (fax)
✉seacofmobile@zebra.net
http://www.home.hiwaay.net/~seachsv/
1,2,3,4

ALASKA

***PARENTS, Inc.**
4743 E. Northern Lights Blvd.
Anchorage, AK 99508
(907) 337-7678
(907) 337-7671 (fax)
✉parents@parentsinc.org
http://www.parentsinc.org

ARIZONA

***RAISING Special Kids**
4750 N. Black Canyon, Ste. 101
Phoenix, AZ 85017
(800) 237-3007 (AZ only)
(602) 242-4366 (voice/TDD)
(602) 242-4306 (fax)
✉peggys@raisingspecialkids.org
1,2,3,4,5

ARKANSAS

Parent to Parent
Arc of Arkansas
2004 Main St.
Little Rock, AR 72206
(501) 375-7770
(501) 372-4621 (fax)

CALIFORNIA

H.E.A.R.T.S. Connection Family Resource Center
3101 N. Sillect Ave., Ste.115
Bakersfield, CA 93308
(800) 210-7633
(661) 328-9055 x. 282
(661) 328-9940 (fax)
✉heartsfrc@igalaxy.net
1,2,3,4

Humboldt Child Care Council
The Special Needs Connection
805 7th St.
Eureka, CA 95501
(800) 795-3554 (CA only)
(707) 444-8293
(707) 444-8298 (fax)
✉jmcleod@hccc1.org
1,2,3,4

Exceptional Parents Unlimited Family Resource Center
4440 North First Street
Fresno, CA 93726
(559) 229-2000
(559) 229-2956 (fax)
✉epu1@exceptionalparents.com

Carolyn Kordich Family Resource Center
1135 W. 257th St.
Harbor City, CA 90710
(310) 325-7288 (phone/fax)
✉ckfrc@worldnet.att.net
2,3,4

Families Caring for Families
Family Resource Center
113 W. Pillsbury St., Ste. A1
Lancaster, CA 93534
(661) 949-1746
(661) 948-7266 (fax)
✉FCF2001@aol.com
1,2,3,4,5,7,8

Challenged Family Resource Center
6738 N. Sultana Dr.
Livingston, CA 98334
(800) 344-6347
(209) 394-4610
(209) 394-4720 (fax)
✉bawalsh@mcoe.merced.k12.ca.us
1,2,3,4

South Central Los Angeles Regional Center For Developmentally Disabled Persons, Inc.
2160 W. Adams Blvd.
Los Angeles, CA 90018
(213) 734-1884
(213) 730-0793 (fax)

CARE Parent Network
1350 Arnold Dr., Ste. 203
Martinez, CA 94553
(800) 281-3023 (Bay Area only)
(925) 313-0999
(925) 370-8651 (fax)
1,2,3,4

***Family Focus Resource Center**
18111 Nordhoff St.
Northridge, CA 91330-8265
(818) 677-5575
(818) 677-5574 (fax)
✉family.focus@csun.edu
http://www.csun.edu/~ffrc
1,2,3,4

MATRIX: Parent Network and Family Resource Center
94 Galli Dr., Ste. C
Novato, CA 94903
(415) 884-3535
(415) 884-3555 (fax)
✉matrix@matrixparents.org
http://www.matrixparents.org

Rainbow Connection
500 Esplanade Dr., Ste. 500
Oxnard, CA 93030
(800) 332-3679
(805) 485-9643
(805) 988-9521 (fax)
✉jordan@jetlink.net

Matrix Family Resource Center
5350 Commerce Blvd, Ste J
Rohnert Park, CA 94928
(707) 586-3314
(707) 584-3438 (fax)
✉SonomaCo@matrixparents.org
http://www.matrixparents.org

Warmline Family Resource Center
1010 Hurley Way Suite 290
Sacramento CA 95825
(800) 660-7995 (Six-County area)
(916) 631-7995
1,2,3,4

Peaks and Valleys
Family Resource Center
c/o Bard Blades School
1145 Acosta St.
Salinas, CA 93905
(800) 400-2937
(891) 424-2937
(831) 771-9132 (fax)
✉peaks@monterey.k12.ca.us

Early Start Family Resource Network
PO Box 6127
San Bernardino, CA 92412-6127
(800) 974-5553 (local only)
(909) 890-4791
(909) 890-4709 (fax)
✉esfrn@yahoo.com
http://www.inlandrc.org

Exceptional Family Resource Center
9245 Sky Park Ct., Ste. 130
San Diego, CA 92123
(877) 268-8252 (CA only)
(858) 292-9092
(858) 268-4275 (fax)
✉efrc@mail.sdsu.edu
1,2,3,4

Parents Helping Parents
594 Monterey Blvd.
San Francisco, CA 94127-2416
(415) 841-8820
(415) 841-8824 (fax)

Support for Families of Children with Disabilities
2601 Mission St., #710
San Francisco, CA 94110
(415) 282-7494
(415) 282-1226 (fax)
✉sfcdmiss@aol.com

Comfort Connection
Family Resource Center
801 Civic Center Dr. W.
Santa Ana, CA 92702
(888) 372-2229 (CA only)
(714) 558-5400
(714) 542-5634 (fax)

Family Support Network
1850 E. 17th St., Ste. 104
Santa Ana, CA 92705
(714) 543-7600
(714) 543-2766 (fax)
✉fsnca@prodigy.net
2,3,4,7

KEY TO SERVICES

1	Periodical/newsletter
2	Informational materials
3	Networking/matching
4	Referrals to local resources
5	Local chapters
6	National conferences
7	National advocacy efforts
8	Fund research
9	Maintain research registry

United Cerebral Palsy Association of Orange County
3010 W. Harvard St.
Santa Ana, CA 92704-3914
(714) 557-1291
(714) 546-0943 (fax)
1,2,3,4,7,8

Family First Program
Alpha Resource Center
4501 Cathedral Oaks Rd.
Santa Barbara, CA 93110
(805) 683-2145
(805) 967-3647 (fax)
✉arcofsb@silcom.com
Parents Helping Parents

The Family Resource Center
3041 Olcott St.
Santa Clara, CA 95054-3222
(408) 727-5775
(408) 727-0182 (fax)
✉info@php.com
http://www.php.com

Special Connections Family Resource Center
984 Bostwick Ln.
Santa Cruz, CA 65062
(831) 464-0669
(831) 464-0779 (fax)

Phase One
Advocacy Resource-Sonoma County, Inc.
PO Box 219
Santa Rosa, CA 95402-0219
(877) 694-4335
(707) 578-6070
(707) 578-0810 (fax)
1,2,3,4,5,6,7

Family Resource Network
5250 Claremont Ave., 237
Stockton, CA 95207
(800) 847-3030
(209) 472-3674
(209) 472-3673 (fax)
1,2,3,4,5

Harbor Regional Center
21231 Hawthorne Blvd.
Torrance, CA 90503
(310) 543-0691
(310) 540-8471(fax)
✉frc-library@hddf.com
1,2,3,4,5

The Parents' Place
Family Resource Center
1500 W. Covina Pkwy., Ste. 207
West Covina, CA 91790-2708
(800) 422-2022
(626) 856-8861
(626) 337-2736 (fax)
✉empower@gte.net
1,2,3,4

COLORADO

Speech, Language, & Hearing Center
University of Colorado at Boulder
Campus Box 409
Boulder, CO 80309-0409
(303) 492-5375
(303) 492-1355 (TDD)
(303) 492-3274 (fax)
✉susan.moore@colorado.edu
✉dowell@spot.colorado.edu
http://www.colorado.edu/slhs

Resources for Young Children and Families, Inc.
1120 N. Circle Dr., Ste. 19
Colorado Springs, CO 80909
(719) 577-9190
(719) 577-9482 (fax)
http://www.rycf.org
1,2,3,4

Denver Early Childhood Connections
124 W. 5th Ave.
Denver, CO 80204
(303) 744-9193
(303) 744-9502 (fax)
1,2,3,4

El Groupo Vida
Attn: Ellie Valdez-Honeyman
PO Box 16347
Denver, CO 80216
(303) 295-0628
(303) 295-7850 (fax)

***Parent to Parent of Colorado**
c/o UCP of Colorado
2200 Jasmine St.
Denver, CO 80222
(303) 627-8888
(203) 627-1265 (fax)
http://www.p2p_co.org

Little People of America
Front Range Chapter
7117 E. Euclid Dr.
Englewood, CO 80111
(303) 740-8555

The Disability Connection and RAFT, Larimer County's Early Childhood Connection
PO Box 270714
Ft. Collins, CO 80527
(970) 229-0224
(970) 229-0242 (fax)
✉bstuts@fornet.org
1,2,3,4

Mile High Down Syndrome Assoc.
PO Box 620847
Littleton, CO 80162
(303) 797-1699
(303) 336-5669 (fax)
✉mhdsa@aol.com
http://www.mhdsa.org
1,2,3,4

Delta/Montrose/Ouray
Parent to Parent
2091 E. Locust Rd.
Montrose, CO 81401
(970) 249-2878
(970) 252-0544 (fax)
✉children@gj.net

HELP Parent Support Group Hope & Education for Loving Parents
378 S. Falcon
Pueblo West, CO 81007
(719) 545-2282
(719) 547-1282 (fax)
✉fastgram@aol.com

Parents Supporting Parents
PO Box 2656
Vail, CO 81658
(970) 926-6015 (phone/fax)

Parents Supporting Parents of Garfield and Pitkin County
PO Box 784
Silt, CO 81652
(970) 876-5768
(970) 876-5204 (fax)

CONNECTICUT

Lower Fairfield Parent to Parent Network
The Arc of Greenwich
50 Glenville St.
Greenwich, CT 06831
(203) 531-1880
(203) 846-9581
(203) 698-9059 (fax)
✉ross@arcgreenwich.org

Parent to Parent Network of Connecticut
The Family Center
Dept. of Connecticut Children's Medical Center
282 Washington Ave.
Hartford, CT 06106
(860) 545-9021
(860) 545-9002 (TDD)
(860) 545-9201 (fax)
✉mcole@ccmckids.org
http://www.ccmckids.org

***(PATH)/Parent to Parent of CT**
PO Box 611
Trumbull, CT 06611
(203) 459-4687
(800) 399-PATH (in CT only)
(203) 459-1989 (fax)
✉path03@aol.com
1,2,3,4,5

DELAWARE

Parent Information Center of Delaware, Inc
1046 S. DuPoint Highway
Dover, DE 19901
(302) 674-0184
(302) 674-0187 (fax)

Parent Information Center of Delaware, Inc
109 N. Bedford Street
Georgetown, DE 19947
(302) 856-9880
(302) 856-9882 (FAX)

***Parent Information Center of Delaware, Inc.**
700 Barksdale Rd., Ste. 16
Newark, DE 19711
(302) 366-0152
Toll free: (888) 547-4412
(302) 366-0276 (fax)
✉picofdel@picofdel.org
http://www.picofdel.org
1,2,4,7

FLORIDA

***Family Network on Disabilities of FL, Inc.**
2735 Whitney Rd.
Clearwater, FL 33760
(800) 825-5736 (FL only)
(727) 523-1130 (voice/TDD)
(727) 523-8687 (fax)
✉fnd@fndfl.org
http://www.fndfl.org
1,2,3,4,7

Parent to Parent/ Palm Beach County
1201 Australina Ave.
Riviera Beach, FL 33404
(561) 842-3213

GEORGIA

***Parent to Parent of Georgia**
3805 Presidential Pkwy., Ste. 207
Atlanta, GA 30340
(800) 229-2038 (GA only)
(770) 451-5484
(770) 458-4091 (fax)
✉info@parenttoparentofga.org
http://www.parenttoparentofga.org
1,2,3,4; *Support group for Spanish speaking parents*

HAWAII

Hawaii Down Syndrome Congress
419 Keoiana St., Ste. 804
Honolulu, HI 96815
(808) 949-1999
(808) 536-3765 (fax)
✉hawaiidownsyndrome@hawaii.RR.com
1,2,3,4,6

***Hawaii Parent to Parent**
3264 Peterson Court
Honolulu, HI 96818
(866) 834-2081 (phone and fax)
(808) 834-2081 (on Oahu)
hawaiip2p@yahoo.com
1

IDAHO

Parents Reaching Out to Parents
2195 Ironwood Ct.
Coeur d'Alene, ID 83814
(208) 769-1409
(208) 769-1430 (fax)

Parent to Parent, Region 7
1783 Brentwood Drive
Idaho Falls, ID 83402
(208) 524-0123

Palouse Area Parent to Parent
2714 8th Ave.
Lewiston, ID 83501
(208) 746-8599 (phone/fax)
✉famit09@moscow.com
1,2,3,4

***Idaho Parent to Parent**
129 W. 3rd St.
Moscow, ID 83843
(208) 885-3500
(208) 885-3628 (fax)
✉famtog@moscow.com
http://www.parentsreachingout.com
1,2,3,4,5,6

ILLINOIS

Archway, Inc.
PO Box 1180
2751 W. Main
Carbondale, IL 62903
(618) 549-4442
(618) 549-0231 (fax)
1,2,3,4; *Early Intervention, At-Risk, and Lekotek Programs*

Southern Illinois Child and Family Connections
1180 W. Willow
Carbondale, IL 62903
(888) 340-6702
(618) 549-8137 (fax)

Developmental Services Center
1304 W. Bradley
Champaign, IL 61821
(217) 359-0287
(217) 356-9851 (fax)
http://www.dsc-illinois.org

Parent to Parent Network
1530 Lincoln Ave.
Charleston, IL 61920
(217) 348-0127
(217) 348-0740 (fax)
1,2,4

Child and Family Connections
9455 S. Hoyne St.
Chicago, IL 60620
(773) 233-1799
(773) 233-2011 (fax)

***Family Resource Center on Disabilities**
20 E. Jackson Blvd., Ste. 300
Chicago, IL 60604
(800) 952-4199 (IL only)
(312) 939-3513
(312) 939-3515 (TDD)
(312) 939-7297 (fax)
1,2,3,4,6,7

Next Steps-Parents Reaching Parents
100 W. Randolph, Ste. 8-100
Chicago, IL 60601
(312) 814-4042 (voice/TDD)
(312) 814-2923 (fax)
✉caroldors@aol.com
1,2,3,4

Greater Interagency Council Parent to Parent Support Network
925 W.175th St.
Homewood, IL 60430
(708) 799-2718
(708) 799-7974 (fax)

National Association for Down Syndrome (NADS)
PO Box 4542
Oak Brook, IL 60522-4542
(630) 325-9112
(630) 325-8842 (fax)
1,2,4,5

INDIANA

First Steps Early Intervention of New Horizons
PO Box 98
Batesville, IN 47006
(812) 934-4528 (voice/TDD)
(812) 934-2522 (fax)

Down Syndrome Association of Central Indiana
10792 Downing St.
Carmel, IN 46033-3869
(317) 574-9757 (phone/fax)
2,3,4,5

NEO Fight
4363 Idlewild Ln.
Carmel, IN 46033-4716
(317) 255-5242
(317) 274-2846 (fax)
✉KMarrs@iupi.edu
http://member.tripod.com/~neofight

Down Syndrome Support Association of Southern Indiana (DSSASI)
PO Box 3262
Clarksville, IN 47131
(812) 948-5182

Down Syndrome Association of NWI
2927 Jewett Ave.
Highland, IN 46322
(219) 838-3656
(219) 838-6959 (fax)
✉dsa@netnitco.net
1,2

KEY TO SERVICES

1	Periodical/newsletter
2	Informational materials
3	Networking/matching
4	Referrals to local resources
5	Local chapters
6	National conferences
7	National advocacy efforts
8	Fund research
9	Maintain research registry

PARENT TO PARENT PROGRAMS

***Indiana Parent Information Network**
4755 Kingsway Dr., Ste. 105
Indianapolis, IN 46205
(317) 257-8683
(317) 251-7488 (fax)
✉familynet@aol.com
http://www.ai.org/ipin
1,2,3,4

Future Choices
309 N. High St.
Muncie, IN 47305
(765) 741-3494
(765) 741-8333 (fax)

First Steps for Families
500 8th Ave.
Terre Haute, IN 47804
(812) 231-8419
(812) 231-8420
(812) 231-8208 (fax)
✉famnetwork@aol.com

ATTIC Inc.
PO Box 2441
2758 B E. Pine Hill Dr.
Vincennes, IN 47591
(800) 962-8842 (voice/TDD)
(812) 886-0575 (voice/TDD)
(812) 886-1128 (fax)
✉inattic2@aol.com

Knox County Advocates
1806 Indiana Ave.
Vincennes, IN 47591
(812) 882-0375
(812) 886-0575
(812) 886-1128 (fax)
✉INATTIC1@aol.com

Family Resource Center of Southeast Indiana
4101 Timberview Rd.
West Harrison, IN 47060
(812) 637-1445
3,4

IOWA

Autism Society of the Quad Cities
PO Box 472
Bettendors, IA 52722-0008
(319) 386-6359
(319) 359-5967 (fax)
✉gkarp@saunix.sau.edu

Family Educator Connection
Area Education Agency 7
3706 Cedar Heights Dr.
Cedar Falls, IA 50613
(319) 273-8265
(319) 273-8275 (fax)
✉dhansen@aea7.k12.ia.us

The Arc of East Central Iowa
Pilot Parents
214 First St. SW
Cedar Rapids, IA 52404
(800) 843-0272 (IA only)
(319) 365-0487
(319) 365-9938 (fax)

Tourette Syndrome
2101 O Ave. NW
Cedar Rapids, IA 52405
(319) 396-0210

Parent Educator Connection Program
Resource Center for Issues in Special Ed.
Drake University
2507 University Ave.
Des Moines, IA 50311-4505
(515) 271-3936
(515) 271-4185 (fax)
✉deb.samson@drake.edu
karen.martens@drake.edu
3,4

Area Education Agency (AEA) 5
1235 5th Ave. S.
Fort Dodge, IA 50501
(515) 574-5423
(515) 574-5508 (fax)
✉mshimkat@aea5.k12.ia.us
http://www.aea5.k12.ia.us

Tourette Syndrome Association of Iowa
307 S. 5th St.
Marshalltown, IA 50158
(515) 753-4157

Parent Educator Connection
Area Education Agency 4
1382 4th Ave. NE
Sioux Center, IA 51250
(800) 572-5073
(712) 772-4374
(712) 722-1643 (fax)
✉GMiller@aea4.k12.ia.us
1,2,3,4

KANSAS

***Families Together/Parent to Parent of Kansas**
501 Jackson, Ste. 400
Topeka, KS 66603
(800) 264-6343 (voice/TDD, KS only)
(785) 233-4777 voice/TDD)
(785) 233-4787 (fax)
✉family@inlandnet.net
1,2,3,4

KENTUCKY

*Parent Information Network of KY
3004 Taylorsville Rd.
Louisville, KY 40205
(502) 479-7465
(502) 452-2145 (fax)
http://www.kyp2p.org

LOUISIANA

***Families Helping Families of Greater New Orleans/Project Prompt**
4323 Division St., Ste. 110
Metairie, LA 70002-3179
(800) 766-7736 (LA only)
(504) 888-9111
(504) 888-0246 (fax)
✉fhfgno@ix.netcom.com
1,2,3,4

MAINE

Cumberland County Parent Awareness, Inc.
PO Box 6505
Portland, ME 04102
(207) 878-0523

Southern Maine Parent Awareness, Inc.
886 Main St., Suite 303
Sanford, ME 04073
(800) 564-9696 (ME only)
(207) 324-2337
(207) 324-5621 (fax)
✉support@somepa.org
1,2,3,4

MARYLAND

Maryland Infant and Toddlers Program Family Support Network
Maryland State Dept. of Education
200 W. Baltimore, 4th Fl.
Baltimore, MD 21201
(410) 767-0261
(410) 333-2661 (fax)

National Organization of Parents of Blind Children
1800 Johnson St.
Baltimore, MD 21230
(410) 659-9314
(410) 685-5653 (fax)
✉BCheadle@nfb.org
http://www.nfb.org

Epilepsy Foundation of America
4351 Garden City Dr.
Landover, MD 20785
(800) 332-1000
(800) 332-2070 (TDD)
(301) 577-2684 (fax)
✉postmaster@efa.org

The Arc Family Connection Parent to Parent Program
11600 Nebel St.
Rockville, MD 20852
(301) 984-5777
(301) 816-2429 (fax)

MASSACHUSETTS

Federation for Children with Special Needs
1135 Tremont St.
Boston, MA 02120
(800) 331-0688 (MA only)
(617) 236-7210
(617) 572-2094 (fax)
✉fcsninfo@fcsn.org
http://www.fcsn.org

Greater Boston Assoc. for Citizens with Mental Retardation and Related Disabilities
1505 Commonwealth Ave.
Boston, MA 02135-3605
(617) 783-3900
(617) 783-9190 (fax)
✉bostonarc@aol.com

National Tay-Sachs and Allied Diseases Association
2001 Beacon St., Ste. 204
Boston, MA 02135
(800) 906-8723
(617) 277-4463
(617) 277-0134 (fax)
✉NTSD-boston@worldnet.att.net
http://www.ntsad.org
1,2,3,4,5,6,7,8

***Family TIES**
DPH-Southeast Office
109 Rhode Island Rd.
Lakeville, MA 02347
(508) 947-1231
(800) 905-8437 (MA only)
(508) 947-0977 (TDD)
(617) 727-9296 (fax)
http://www.massfamilyties.org
2,3,4

Massachusetts Down Syndrome Congress
PO Box 866
Melrose, MA 02176
(800) 664-6372 (MA only)
(505) 755-6800
(508) 278-4435 (fax)
http://www.mdsc.org

MICHIGAN

***Family Support Network of MI**
Parent Participation Program-MDCH
200 6th St., 3rd Fl.
S. Tower, Ste. 316
Detroit, MI 48226-2495
(800) 359-3722
(313) 256-2605 (fax)

MINNESOTA

Arc Anoka
1201 89th Ave. NE
Blaine, MN 55434
(763) 783-4958
(763) 785-8891 (fax)

Arc Suburban
1526 E. 122nd St.
Burnsville, MN 55337-6804
(952) 890-3057
(952) 890-3527 (fax)
✉cdendaas@arcars.org
1,2,3,4,5,6

Family Track Services or FAS/FAE or RESPITE Resources
Arc Northland
424 W. Superior St., Ste. 201
Duluth, MN 55802
(800) 317-6475
(218) 726-4725
(218) 726-4732 (fax)
✉arcdu@aol.com
1,2,3,4,5,6,7

Windmill Project
128 W. Junius Ave
Fergus Falls, MN 56537
(218) 736-4982
(218) 739-0078 (fax)
✉tbeck_wm_atn@hotmail.com
1,2,3,4,5

Family to Family Network
Arc Hennepin-Carver
4301 Hwy. 7, Ste. 140
Minneapolis, MN 55416-5810
(612) 920-0855
(612) 920-1480 (fax)
http://www.archennpincarver.org
1,2,4,

Turner's Syndrome Society
1313 SE 5th St., Ste. 327
Minneapolis, MN 55414
(800) 365-9944
(612) 379-3607
(612) 379-3619 (fax)
✉tesch@turner-syndrome.us.org

Family Liaison Project
Arc of Southeastern MN
903 W. Center St., #140
Rochester, MN 55902
(888) 732-8520
(507) 287-2032
(507) 287-2063 (fax)
1,2,3,4,5,7

Arc Ramsey
770 Transfer Rd., Ste. 26
St. Paul, MN 55114
(651) 523-0876
(651) 523-0829 (fax)

Parents for Parents
Mail Stop 70-404
345 N. Smith Ave.
St. Paul, MN 55102
(651) 220-6731
(651) 220-6707 (fax)
✉Pat.Schaffner@childrenshc.org

MISSOURI

***Disabilities Advocacy & Support Network**
The Network
1515 E. Pythian
PO Box 5030
Springfield, MO 65801-5030
(417) 895-7464
(417) 895-7430 (TDD)
(417) 895-7412 (fax)
2,3,4,5

Positive Solutions for Life Challenges
Rt. 3, Box 441
Warshaw, MO 65355
(660) 438-6990

MONTANA

Parents, Lets Unite for Kids
516 N. 32nd St.
Billings, MT 59101
(800) 222-7585 (MT only)
(406) 255-0540
(406) 255-0523 (fax)
✉plukinfo@pluk.org
http://www.pluk.org
1,2,3,4

Quality Life Concepts
PO Box 2506
Great Falls, MT 59403
(406) 452-9531
(406) 453-5930 (fax)

CO-TEACH/Division of Educational Research and Service
School of Education
University of Montana
Missoula, MT 59812
(406) 243-5344
(406) 243-5636
(406) 243-2797 (fax)
✉coteach@selway.umt.edu

NEBRASKA

Parent Support Group
123 S. Webb Rd.
PO Box 4904
Grand Island, NE 68802
(308) 385-5900 x 190
(308) 385-5797 (fax)
✉msheen@genie.esu10.k12.ne.us

Kearney Public Schools
310 W. 24th
Kearney, NE 68847
(308) 237-6022
(308) 237-6014 (fax)
✉clarsen@genie.esu10.k12.ne.us

Individual and Family Support The Arc of Lincoln & Lancaster County
645 M St., Ste. 19
Lincoln, NE 68508
(402) 477-6925
(402) 477-6927 (fax)

Parents Encouraging Parents
NE Dept. of Education
301 Centennial Mall S.
PO Box 94987
Lincoln, NE 68509-4987
(402) 471-2471 (voice/TDD)
(402) 471-5022 (fax)
✉gwright@edneb.org

Pilot Parent's Program
The Nebraska Parents Center
1941 S. 42nd St., Ste. 122
Omaha, NE 68105-2942
(800) 284-8520
(402) 346-5220
(402) 346-5253 (fax)
http://www.neparentcenter.org

NEVADA

***Nevada Parent Network**
University of Nevada-Reno
COE, REPC/285
Reno, NV 89557
(800) 216-7988
(775) 784-4921
(775) 784-4997 (fax)
✉cheryls@unr.edu
http://www.scs.unr.edu/repc/npn

NEW HAMPSHIRE

***Parent to Parent of NH**
12 Flynn St.
Lebanon, NH 03766
(800) 698-5465 (NH, VT, ME)
(603) 488-6393
(603) 448-6311 (fax)
✉parent.to.parent@Dartmouth.edu
http://www.parenttoparentnh.org
1,2,3,4,6,7

NEW JERSEY

***Family Support Center of NJ**
NJ Statewide Parent to Parent
Lions Head Office Park
35 Beaverson Blvd., Ste. 8A
Brick, NJ 08703
(800) 372-6510 (NJ only)
(732) 262-8020
(732) 262-4373 (fax)
✉FSCNJ@aol.com
http://www.efnj.com
1,2,3,4

SPEAK Support for Parents with Exceptionally Abled Kids
PO Box 2116
Flemington, NJ 08822
(908) 788-7317
(908) 806-7909 (fax)
✉bluerainbow@earthlink.net
http://www.community.nj.com/cc/speak

NEW MEXICO

***Parents Reaching Out (PRO)**
1000 A Main St.
Los Lunas, NM 87031
(800) 524-5176 (voice/TDD)
(505) 865-3700 (voice/TDD)
(505) 865-3737 (fax)
✉nmproth@aol.com
http://www.parentsreachingout.org

NEW YORK

***Parent to Parent of NY State**
500 Balltown Rd.
Schenectady, NY 12304
(800) 305-8817 (for parents)
(518) 381-4350
(518) 382-1959 (fax)
✉parent2par@aol.com
http://www.parenttoparentnys.org

NORTH CAROLINA

***Family Support Network OF NC**
CB #7340
U of NC Chapel Hill
Chapel Hill, NC 27599-7340
(800) 852-0042 (NC only, voice/TDD)
(919) 966-2841
(919) 966-2916 (fax)
✉cdr@med.unc.edu
http://www.fsnc.med.unc.edu
2,3,4,5

NORTH DAKOTA

***Family to Family Network of ND**
UND School of Medicine and Health Sciences
PO Box 9037-PT Dept
Grand Forks, ND 58202-9037
(701) 777-2359
(701) 777-2353 (fax)
✉ndf2f@medicine.nodak.edu
http://www.med.nodak.edu/depts/pt/f2f/
1,2,3,4

OHIO

Ohio Protection and Advocacy Org.
5350 Brookpark Ave.
Cleveland, OH 44134
(216) 398-5501
(216) 398-5505 (fax)

***Family Information Network**
Ohio Department of Health/BEIS
246 N. High Street, 5th Floor
Columbus, OH 43266-0118
(614) 644-8389
(614) 728-9163 (fax)
1,2,3,4

Ohio Brain Injury Assoc.
1335 Dublin Rd., Ste. 217D
Columbus, OH 43215-1000
(800) 686-9563 (OH only)
(866) OHIO- BIA (644-6242)
(614) 481-7100
(614) 481-7103 (fax)
✉help@biaoh.org

Celebrating Families of Children & Adults with Special Needs
16 Vassar Dr.
Dayton, OH 45406-4928
(937) 275-0990
(937) 275-0277 (fax)
✉families@erinet.com

Down Syndrone and Related Disabilities
1444 Beaver Creek Ln.
Kettering, OH 45429-3704
(937) 294-1240
(937) 294-2545 (fax)
✉padixon@ciscom.net

Family Information Network
143 Northwest Ave., Bldg. A
Tallmadge, OH 44278
(330) 633-2055
(330) 633-2658 (fax)
1,2,3,4

OREGON

***Oregon Cope Project**
999 Locust St. NE
Salem, OR 97303
(888) 505-COPE
(503) 581-8156
(503) 391-0429 (fax)
✉orcope@open.org
http://www.open.org/orcope
1,2,3.4,5 *(statewide staff)*

PENNSYLVANIA

***Parent to Parent of PA**
Gateway Corporate Center
6340 Flank Dr. #600
Harrisburg, PA 17112
(717) 540-4722
(717) 657-5983 (fax)
✉parent2parent@southstar.org
http://www.parenttoparent.org
1,2,3,4,5,6

Arc Allegheny
711 Bingham St.
Pittsburgh, PA 15203
(412) 995-5000
(412) 995-5001 (fax)
http://www.arcallegheny.org
1,2,3,4,5,6

RHODE ISLAND

Down Syndrome Society of RI
99 Bald Hill Rd.
Cranston, RI 02920
(401) 463-5751
(401) 463-5337 (fax)
✉dssri@aol.com
http://www.dssri.org
1,2,3,4

Rhode Island Parent Information Network
175 Main St.
Pawtucket, RI 02860
(800) 464-3399 (RI only)
(401) 727-4144
(401) 727-4040 (fax)
http://www.ripin.org
1,2,3,4

Trudeau Early Intervention Program-Kent County Office
J Arthur Trudeau Memorial Ctr.
250 Commonwealth Ave.
Warwick, RI 02886
(401) 823-1731 x 42
(Parent Consultant)
(401) 823-1849 (fax)
1,2,3,4

SOUTH CAROLINA

***Family Connection of SC, Inc.**
2712 Middleburg Dr., Ste. 103-B
Columbia, SC 29204
(800) 578-8750 (SC only)
(803) 252-0914 (Columbia)
(864) 331-1340 (Greenville)
(843) 662-0675 (Florence)
(803) 799-8017 (fax)
✉famconn@mindspring.com
http://www.familyconnectionsc.org
1,2,3,4,7

SOUTH DAKOTA

***South Dakota Parent Connection Inc.**
3701 W. 49th St., Ste. 200 B
Sioux Falls, SD 57106
(800) 450-4553
(605) 361-3171
(605) 361-2928 (fax)
✉sdparent@sdparent.org
2,3,4

TENNESSEE

***Parents Encouraging Parents (P.E.P.)**
Central Office Cordell Hull Bldg.
425 5th Ave. N., 5th Fl.
Nashville, TN 37247-4750
(615) 741-0353
(615) 741-1063 (fax)
✉srothacker@mail.state.tn.us
2,3,4,5,9

TEXAS

Parent Case Management Prog.
4601 Hartford
Abilene, TX 79605
(915) 793-3501
(915) 793-3549 (fax)
✉jowens@wtrc.com
1,2,3,4

Uniting Parents
Parent Case Management Program
301 South Polk, Suite 740
Amarillo, TX 79101
(888) 892-2273 (national)
(806) 333-1735
(806) 337-1702 (fax)
✉unitingparents@cohs.net

***Pilot Parent Family Resource Center**
2818 San Gabriel
Austin, TX 78705-3598
(512) 476-7044
(512) 476-9054 (fax)
✉pilotparent@arcofthecapitalarea.org

Parent to Parent Network of Texas
✉p2poftexas@arcofthecapitalarea.org
1,2,3,4

Partners Resource Network, Inc
1090 Longfellow Dr., Ste. B
Beaumont, TX 77706-4889
(800) 866-4726 (TX only)
(409) 898-4684
(409) 898-4816 (TDD)
(409) 898-4869 (fax)
✉txprn@pnx.com
1,2,3,4

Tarrant Society for Deaf Children
6416 Canyon Circle
Ft. Worth, TX 76133
(817) 346-0421

Family to Family Network
4423 Shadowdale
Houston, TX 77041
(713) 466-6304
(713) 466-9547 (fax)
✉f2fnetwork@aol.com
http://www.neosoft.com/~fam2fam

Parent Case Management Prog.
3001 S. Jackson
San Angelo, TX 76904
(915) 223-6350
(915) 223-6408 (fax)

Any Baby Can of San Antonio
217 Howard
San Antonio, TX 78212
(210) 227-0170
(210) 227-0812 (fax)
✉framirez@anybabycansa.org
http://www.anybabycansa.org
1,2,3,4

UTAH

Parent to Parent
U of Utah Hospital
50 N. Medical Dr., Ste. 2553
Salt Lake City, UT 84132
(801) 581-2098
(801) 561-5060 (fax)
✉becky.hatfields@hsc.utah.edu

The Parent Connection: Parent Support in NICU@ LDSH
Kathie Peterson, Parent Coordinator
LDS Hospital
8th Ave and "C" St.
Salt Lake City, UT 84103
(801) 408-8661
(801) 763-0711
✉ DKPETER@IHC.com

Primary Children's Medical Center Graduate Parents
100 N. Medical Dr.
Salt Lake City, UT 84113
(801) 588-3899
(801) 588-3869 (fax)
✉pcddrigg@ihc.com

VERMONT

***Parent to Parent of VT**
1 Main St., #69 Champlain Mill
Winooski, VT 05404
(800) 800-4005
(802) 655-3507 (fax)
✉p2pvt@together.net
http://www.partopartvt.org
1,2,3,4,7

VIRGINIA

*Parent to Parent of VA
PO Box 38341
Richmond, VA 23231
(804) 222-1945
(804) 222-3402 (fax)
✉PTPofVA@aol.com

The Arc of VA
6 N. 6th St., Ste. 403
Richmond, VA 23219
(888) 604-2677
(804) 649-8481
(804) 649-3585 (fax)
✉arcf1p@aol.com

WASHINGTON

Parents of Prematures
PO Box 3046
Kirkland, WA 98083
(206) 283-7466

***Parent to Parent (WA & King Co.)**
The Arc-King County
10550 Lake City Way NE, Ste. A
Seattle, WA 98125
(800) 821-5927
(206) 364-8140 (fax)
✉statep2p@aol.com

WISCONSIN

MUMS
National Parent to Parent Program
150 Custer Ct.
Green Bay, WI 54301-1243
(877) 336-5333 (Parents only)
(920) 336-5333
(920) 339-0995 (fax)
✉mums@netnet.net

Bridges for Families
Birth to Three Early Intervention
A127 Waisman Ctr
1500 Highland Ave.
Madison, WI 53705
(608) 263-9907
(608) 263-9237 (TDD)
(608) 265-9118 (fax)
✉BRIDGES@Waisman.wisc.edu
1,2,3,4

Family Empowerment Network Families Affected by FAS/FAE
519 Lowell Hall
610 Langdon St.
Madison, WI 53703
(800) 462-5254
(608) 262-6590
(608) 265-3352 (fax)
✉fen@mail.dcs.wisc.edu

The Arc of Racine–Parents Helping Parents
818 Sixth St.
Racine, WI 53403
(414) 634-6303
(414) 635-2640 (fax)
✉thearc@rootcom.net
1,2,3,4

WYOMING

Parent Information Center
5 N. Lobban
Buffalo, WY 82834
(800) 660-9742 (WY only)
(307) 684-2277
(307) 684-5314 (fax)
✉tdawson@wpic.org
1,2,3,4,7

KEY TO SERVICES

1	Periodical/newsletter
2	Informational materials
3	Networking/matching
4	Referrals to local resources
5	Local chapters
6	National conferences
7	National advocacy efforts
8	Fund research
9	Maintain research registry

93

PARENT TRAINING & INFORMATION CENTERS

Parent centers in each state provide training and information to parents of infants, toddlers, school-aged children, and young adults with disabilities and the professionals who work with their families. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. To reach the parent center in your state, you can contact **Alliance Coordinating Office:** PACER Center, 8161 Normandale Blvd, Minneapolis, MN 55437-1104; phone (888) 248-0822 or (952) 838-9000; (952) 838-0190 (TDD); (952) 838-0199 (fax); ✉alliance@taalliance.org; http://www.taalliance.org. The Technical Assistance Alliance for Parent Centers (the Alliance) coordinates the delivery of technical assistance to the Parent Training and Information Centers and the Community Parent Resource Centers through four regional centers.

Using this directory

When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the ✉ symbol. Web sites are listed with the standard **http://** before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

(CPRC)=Community Parent Resource Center

REGIONAL CENTERS

Alliance Coordinating Office:
PACER Center
8161 Normandale Blvd
Minneapolis, MN 55437-1104
(888) 248-0822
(952) 838-9000 - (Voice)
(952) 838-0190 - (TDD)
(952) 838-0199 - (Fax)
✉alliance@taalliance.org
http://www.taalliance.org
Paula Goldberg, Executive Director
Sharman Davis Barrett, Project Co-Director, ✉sharman@pacer.org
Sue Folger, Project Co-Director; ✉sfolger@pacer.org
Kelly Lorenz, ✉klorenz@pacer.org
Dao Xiong, Multicultural Advisor; ✉dxiong@pacer.org
Jesús Villaseñor, Multicultural Advisor; ✉jesus@pacer.org

Northeast Regional Center
Parent Information Center
P.O. Box 2405
Concord, NH 03302-2405
(603) 224-7005 (Voice)
(603) 224-4379 (Fax)
✉picnh@aol.com
Judith Raskin, Regional Director
Lillye Ramos Spooner,
Multicultural TA Coordinator
CT, DE, DC, ME, MD, MA, NH, NJ, NY, PA, Puerto Rico, RI, US VI, VT

Midwest Regional Center
Ohio Coalition for the Education of Children with Disabilities (OCECD)
Bank One Building
165 West Center Street, Suite 302
Marion, OH 43302-3741
(740) 382-5452 (Voice)
(740) 383-6421 (Fax)
✉ocecd@gte.net
Margaret Burley,
Regional Co-Director
Lee Ann Derugen,
Regional Co-Director
Dena Hook,
Technical Assistance Coordinator
Laura Glenn,
Multicultural TA Coordinator
CO, IL, IA, IN, KS, KY, MI, MN, MO, NE, ND, OH, SD, WI

South Regional Center
Exceptional Children's Assistance Center (ECAC)
907 Barra Row, Suite 102-103
Davidson, NC 28036
(704) 892-1321
(704) 892-5028 (Fax)
✉ECAC1@aol.com
Connie Hawkins,
Regional Director
Judy Higginbotham, Technical
Assistance Coordinator
Johnny Allen,
Multicultural TA Coordinator
AL, AR, FL, GA, LA, MS, NC, OK, SC, TN, TX, VA, WV

West Regional Center
Matrix Parent Network and Resource Center
94 Galli Drive, Suite C
Novato, CA 94949
(415) 884-3535
(415) 884-3555 (Fax)
✉alliance@matrixparents.org
Alan Kerzin, Regional Director
Nora Thompson, Technical
Assistance Coordinator
Patricia Valdez,
Multicultural TA Coordinator
AK, AZ, Department of Defense Dependent Schools (DODDS), CA, HI, ID, MT, NV, NM, OR, Pacific Jurisdiction, UT, WA, WY

ALABAMA

Special Education Action Committee, Inc.
Carol Blades, Director
P.O. Box 161274
Mobile, AL 36616-2274
(334) 478-1208 (Voice & TDD)
(800) 222-7322 (AL only)
(334) 473-7877 (Fax)
✉seacofmobile@zebra.net
http://hiwaay.net/~seachsv/

ALASKA

PARENTS, Inc.
Faye Nieto
4743 E. Northern Lights Blvd.
Anchorage, AK 99508
(907) 337-7678 (Voice)
(907) 337-7629 (TDD)
(800) 478-7678 (in AK)
(907) 337-7671 (Fax)
✉parents@parentsinc.org
http://www.parentsinc.org

AMERICAN SAMOA

American Samoa PAVE
Fa' Anati Penitusi
P.O. Box 6844
Pago Pago, AS 96799
(011) 684-699-6946
(011) 684-699-6952 (Fax)
✉SAMPAVE@samoatelco.com
http://www.taalliance.org/ptis/amsamoa/

ARIZONA (CPRC)

Pilot Parents of Southern Arizona
Lynn Kallis
2600 North Wyatt Drive
Tucson, AZ 85712
(520) 324-3150
(520)324-3152 (Fax)
✉ppsa@pilotparents.org
http://www.pilotparents.org

RAISING Special Kids
Joyce Millarde-Hoie
4750 N. Black Canyon Hwy,
Suite 101
Phoenix, AZ 85017-3621
1-800-237-3007
(in AZCentral and Northern AZ)
(602) 242-4366 (Voice & TDD)
(602) 242-4306 (Fax)
✉info@raisingspecialkids.org
http://www.info@raisingspecialkids.org

ARKANSAS

Arkansas Disability Coalition
Wanda Stovall
1123 University Ave., Suite 225
Little Rock, AR 72204-1605
(501) 614-7020 (Voice & TDD)
(800) 223-1330 (AR only)
(501) 614-9082 (Fax)
✉adc@alltel.net
http://www.adcpti.org
Statewide With FOCUS AR

FOCUS, Inc.
Ramona Hodges
305 West Jefferson Ave.
Jonesboro, AR 72401
(870) 935-2750 (Voice)
(888) 247-3755
(870) 931-3755 (Fax)
✉focusinc@ipa.net
http://www.grnco.net/~norre/
With Arkansas Disability
Coalition AR

CALIFORNIA

California Down Symdrome Association of San Diego
Joyce Clark
PO Box 881883
San Diego, CA 92168
(619) 276-44946
(619) 276-4494 (Fax)
✉dsad@carthlink.net

DREDF
Diane Lipton
2212 Sixth Street
Berkeley, CA 94710
(510) 644-2555 (TDD available)
(800) 466-4232
(510) 841-8645 (Fax)
✉dredf@dredf.org
http://www.dredf.org
Northern California
With Parents Helping Parents,
Santa Clara

Exceptional Family Support, Education and Advocacy Center
Debbie Rowell
6402 Skyway
Paradise, CA 95969
(530) 876-8321
(888) 263-1311
(530) 876-0346 (Fax)
✉sea@sunset.net
http://www.sea-center.org

Exceptional Parents Unlimited
Leslie Lee
4440 N. First St
Fresno, CA 93726
(559) 229-2000
(559) 229-2956 (Fax)
✉epu1@cybergate.com
http://www.exceptionalparents.org
Central California

Matrix
Alan Kerzin
94 Galli Drive, Suite C
Novato, CA 94949
(415) 884-3535
(800) 578-2592
(415) 884-3555 (Fax)
✉alliance@matrixparents.org
http://www.matrixparents.org
Northern California
With Parents Helping parents,
Santa Clara

Parents Helping Parents of San Francisco
Lois Jones
594 Monterey Blvd.
San Francisco, CA 94127-2416
(415) 841-8820
(415) 841-8824 (Fax)
vsfphp@earthlink.com
Nine counties in the San Francisco
Bay area

Parents Helping Parents of Santa Clara
Mary Ellen Peterson
3041 Olcott St.
Santa Clara, CA 95054-3222
(408) 727-5775 (Voice)
(408) 727-7655 (TDD)
(408) 727-0182 (Fax)
✉info@php.com
http://www.php.com
Northern California
With Matrix and DREDF

CALIFORNIA (CPRC)

Loving Your Disabled Child
Theresa Cooper
4528 Crenshaw Boulevard
Los Angeles, CA 90043
(323) 299-2925
(323) 299-4373 (Fax)
✉lydc@pacbell.net
http://www.lydc.org
Most of LA County

Parents of Watts
Alice Harris
10828 Lou Dillon Ave
Los Angeles, CA 90059
(323) 566-7556
(323) 569-3982 (Fax)
✉egertonf@hotmail.com
With Loving Your Disabled Child

Support for Families of Children with Disabilities
Juno Duenas
2601 Mission #710
San Francisco, CA 94110-3111
(415) 282-7494
(415) 282-1226 (Fax)
✉jduenas@supportforfamilies.org
San Francisco

TASK
Joan Tellefsen / Marta Anchondo
100 West Cerritos Ave.
Anaheim, CA 92805
(714) 533-8275
(714) 533-2533 (Fax)
✉taskca@yahoo.com
Southern California

TASK, San Diego
Joan Tellefsen
3750 Convoy St., Suite 303
San Diego, CA 92111-3741
(858) 874-2386
(858) 874-2375 (Fax)
✉taskd1@aol.com
City of San Diego
and Imperial counties

Vietnamese Parents of Disabled Children Assoc., Inc. (VPDCA)
My-Lihn Duvan, President
7526 Syracuse Ave
Stanton, CA 90680
(310) 370-6704
(310) 542-0522 (Fax)
✉luyenchu@aol.com
With Loving Your Disabled Child

COLORADO

The Denver Outreach Project
Jerri Miller
1177 Grant Street, Suite 104
Denver, CO 80203
(303) 864-1900
(303) 864-0035 (Fax)
✉jmiller@peakparent.org
http://www.peakparent.org

PEAK Parent Center, Inc.
Barbara Buswell
611 North Weber, Suite 200
Colorado Springs, CO 80903
(719) 531-9400 (Voice)
(719) 531-9403 (TDD)
(800) 284-0251
(719) 531-9452 (Fax)
✉info@peakparent.org
http://www.peakparent.org

CONNECTICUT

Connecticut Parent Advocacy Center
Nancy Prescott
338 Main Street
Niantic, CT 06357
(860) 739-3089 (Voice & TDD)
(800) 445-2722 (in CT)
(860) 739-7460 (Fax) (Call first to dedicate line)
✉cpacinc@aol.com
http://www.cpacinc.org

DELAWARE

Parent Information Center of Delaware (PIC/DE)
Marie-Anne Aghazadian
700 Barksdale Road, Suite 16
Newark, DE 19711
(302) 366-0152 (Voice)
(302) 366-0178 (TDD)
(888) 547-4412
(302) 366-0276 (Fax)
✉picofdel@picofdel.org
http://www.picofdel.org

DISTRICT OF COLUMBIA

Advocates for Justice and Education
Bethann West
2041 Martin Luther King Ave., SE,
Suite 301
Washington, DC 20020
(202) 678-8060
(888) 327-8060
(202) 678-8062 (Fax)
✉Bethann.West@AJE-DC.org
http://www.AJE-DC.com/
District of Columbia

FEDERATED STATES OF MICRONESIA

KOSRAE Special Parent Network
Canny Palsis
KOSRAE Special Parent Network
PO Box 224
Kosrae, FSM 96944
(691) 370-3032
(691) 370-2232 (Fax)
✉cpclsis@mail.fm

FLORIDA

Family Network on Disabilities
Jan LaBelle
2735 Whitney Road
Clearwater, FL 33760-1610
(727) 523-1130
(800) 825-5736 (FL only)
(727) 523-8687 (Fax)
✉fnd@fndfl.org
http://fndfl.org

FLORIDA (CPRC)

Parent to Parent of Miami, Inc.
Isabel Garcia
c/o Sunrise Community
9040 Sunset Drive, Suite G
Miami, FL 33173
(305) 271-9797
(305) 271-6628 (Fax)
✉PtoP1086@aol.com
Miami Dade and Monroe Counties

GEORGIA

Parents Educating Parents and Professionals for All Children (PEPPAC)
LaVerne Bomar
6613 East Church Street,
Suite 100
Douglasville, GA 30134
(770) 577-7771
(770) 577-7774 (Fax)
✉peppac@bellsouth.net
http://www.peppac.org

HAWAII

AWARE
Jennifer Schember-Lang, Project Director
200 N. Vineyard Blvd., Suite 310
Honolulu, HI 96817
(808) 536-9684 (Voice)
(808) 536-2280 (Voice & TDD)
(800) 533-9684
(808) 537-6780 (Fax)
✉ldah@gte.net

Palau Parent Network
Erma Ngwal
c/o Dottie Kelly
Center on Disability Studies,
University of Hawaii
1833 Kala Kaua Avenue, #609
Honolulu, HI 96815
(808) 945-1432
(808) 945-1440 (Fax)
✉dotty@hawaii.edu
✉patric@palaunet.com

IDAHO

Idaho Parents Unlimited, Inc.
Cheryl Fisher
4696 Overland Road, Suite 568
Boise, ID 83705
(208) 342-5884 (Voice & TDD)
(800) 242-4785
(208) 342-1408 (Fax)
✉ipul@rmci.net
http://home.rmci.net/ipul

Native American Parent Training and Information Center
Chris Curry & Susan Banks
129 East Third
Moscow, ID 83843
(208) 885-3500
(208) 885-3628 (Fax)
✉famtog@moscow.com
Nation-wide resource for Native American families, tribes, and communities as well as parent centers and others needing in formation on this subject.

ILLINOIS

Designs for Change
Donald Moore
29 East Madison, Suite 950
Chicago, IL 60602
(312) 236-7252 (Voice)
(312) 857-1013 (TDD)
(312) 857-9299 (Fax)
✉markse@designsforchange.org
http://www.dfc1.org

Family Resource Center on Disabilities
Charlotte Des Jardins
20 E. Jackson Blvd., Room 300
Chicago, IL 60604
(312)-939-3513 (Voice)
(312-) 939-3519 (TTY & TDY)
(800) 952-4199 (IL only)
(312) 939-7297 (Fax)
✉frcdptiil@ameritech.net
http://www.ameritech.net/users/frcdptiil/index.html

Family T.I.E.S. Network
Carol Saines
830 South Spring
Springfield, IL 62704
(217) 544-5809
(800) 865-7842
(217) 544-6018 (Fax)
✉mrsinclusion@aol.com
http://www.taalliance.org/ptis/fties/

National Center for Latinos with Disabilities
Everado Franco
1915-17 South Blue Island Ave.
Chicago, IL 60608
(312) 666-3393 (Voice)
(312) 666-1788 (TDD)
(800) 532-3393
(312) 666-1787 (Fax)
✉ncld@ncld.com
http://interaccess.com/~ncld/

INDIANA

IN*SOURCE
Richard Burden
809 N. Michigan St.
South Bend, IN 46601-1036
(219) 234-7101
(219) 239-7275 (TDD)
(800) 332-4433 (in IN)
(219)234-7279 (Fax)
✉insourc1@aol.com
http://www.insource.org

IOWA

Access for Special Kids (ASK)
Jule Reynolds
321 E. 6th St
Des Moines, IA 50309
(515) 243-1713
(800) 450-8667
(515) 243-1902 (Fax)
✉ptiiowa@aol.com
http://www.taalliance.org/ptis/ia/

The Parent Partner Community Resource Center Project
Liz Hooley Grantwood
4401 6th Street SW
Cedar Rapids, IA 52404-4499
(800) 332-8488
(319) 399-6457 (Fax)
✉gpettitt@aea10.k12.ia.us
http://www.taalliance.org/ptis/ia/

KANSAS (CPRC)

Families ACT
Nina Lomely-Baker
555 N. Woodlawn
Wichita, KS 67203
(316) 685-1821
(316) 685-0768 (Fax)
✉nina@mhasck.org
http://www.mhasck.org
Sedgwick County and Outlying area

KANSAS

Families Together, Inc.
Connie Zienkewicz
3340 W Douglas, Ste 102
Wichita, KS 67203
(316) 945-7747
(888) 815-6364
(316) 945-7795 (Fax)
✉fmin@southwind.net
http://www.familiestogether-inc.com

KENTUCKY

Kentucky Special Parent Involvement Network (KY-SPIN)
Paulette Logsdon
10301 B Deering Road
Louisville, KY 40272
(502) 937-6894
(800) 525-7746
(502) 937-6464 (Fax)
✉spininc@aol.com

FIND of Louisville
Robin Porter
1146 South Third Street
Louisville, KY 40203
(502) 584-1239
(502) 584-1261 (Fax)
✉training@council-crc.org
http://www.council-crc.org

LOUISIANA (CPRC)

Pyramid Parent Training Program
Ursula Markey
4120 Eve Street
New Orleans, LA 70125
(504) 827-0610
(504) 827-2999 (Fax)
✉dmarkey404@aol.com

LOUISIANA

Project PROMPT
Leah Knight
4323 Division Street, Suite 110
Metairie, LA 70002-3179
(504) 888-9111
(800) 766-7736
(504) 888-0246 (Fax)
✉fhfgno@ix.netcom.com
http://www.projectprompt.com

MAINE

Maine Parent Federation
Janice LaChance
675 Western Avenue
Suite #4
Manchester, ME 04351
(207) 582-2504
(800) 870-7746
(207) 582-3638 (Fax)
✉jlachance@mpf.org
http://www.mpf.org

MARYLAND

Families Involved Together, Inc.
Diane Sakwa
2219 Maryland Avenue
Baltimore, MD 21218-5627
(410) 235-5222
(410) 235-4222 (Fax)
✉diane@familiesinvolved.org

Parents Place of Maryland, Inc.
Josie Thomas
7484 Candlewood Rd Suite S
Hanover, MD 21076-1306
(410) 859-5300 (Voice & TDD)
(410) 859-5301 (Fax)
✉info@ppmd.org
http://www.ppmd.org

MASSACHUSETTS

Federation for Children with Special Needs
Richard Robison
1135 Tremont Street, Suite 420
Boston, MA 02120-2140
(617) 236-7210 (Voice and TDD)
(800) 331-0688 (in MA)
(617) 572-2094 (Fax)
✉fcsninfo@fcsn.org
http://www.fcsn.org/

IPEST
Carol Kennedy
PO Box 4081
Vineyard Haven, MA 02568
(508) 696-5486
(508) 696-5497 (Fax)
✉ipest@adelphia.net

Urban / PRIDE
Charlotte R. Spinkston
1472 Tremont
Roxbury Crossing, MA 02120
(617) 445-3191
(800) 331-0688 (in MA)
(617) 445-6309 (Fax)
✉cspinkstion.urbanpride@att.net

MICHIGAN

CAUSE
Deborah Canja Isom
2365 Woodlake Drive, Suite 100
Okemos, MI 48864
(517) 347-2283
(Voice & TDD & TDY)
(800) 221-9105 (in MI)
(517) 886-9775 (Fax)
✉info@causeonline.org
http://www.causeonline.org

MINNESOTA

Discapacitados Abriendose Caminos
Ana M. Perez de Perez
608 Smith Avenue
St. Paul, MN 55107
(651) 293-1748
(651) 293-1744 (Fax)
✉marlui5459@yahoo.com

PACER Center, Inc.
Paula Goldberg/
Virginia Richardson
8161 Normandale Blvd.
Minneapolis, MN 55437-1044
(952) 838-9000 (Voice);
(952) 838-0190 (TDD)
(800) 537-2237 (in MN)
(952) 838-0199 (Fax)
✉pacer@pacer.org
http://www.pacer.org

MISSISSIPPI

Parent Partners
7 Lakeland Circle Suite 600
Jackson, MS 39216
(601) 982-1988
(800) 366-5707 (in MS)
(601) 982-5792 (Fax)
✉arcpti@parentpartners.org
Parent Partners General box

MISSISSIPPI (CPRC)

Project Empower
Agnes Johnson
136 South Poplar Ave
Greenville, MS 38701
(601) 332-4852
(800) 337-4852
(601) 332-1622 (Fax)
✉empower@tecinfo.com

PARENT TRAINING & INFORMATION CENTERS

MISSOURI

Missouri Parents Act (MPACT)
Janet Jacoby, Executive Director
1 W. Armour Blvd. Suite 302
Kansas City, MO 64111
(816) 531-7070
(800) 743-7634
(816) 531-4777 (Fax)
✉ptijcj@aol.com
http://www.crn.org/mpact/

MONTANA

Parents Let's Unite for Kids
Dennis Moore
516 N. 32nd Street
Billings, MT 59101
(406) 255-0540
(800) 222-7585 (in MT)
(406) 255-0523 (Fax)
✉plukinfo@pluk.org
http://www.pluk.org

NEBRASKA

PTI Nebraska
Glenda Davis
7832 Read Plaza
Omaha, NE 68122
(402) 346-0525 (Voice & TDD)
(800) 284-8520
(402) 346-5253 (Fax)
✉gdavis@neparentcenter.org
http://www.neparentcenter.org

NEVADA

Nevada Parents
Encouraging Parents (PEP)
Karen Taycher
2810 W. Charleston Blvd., Suite G-68
Quail Park IV
Las Vegas, NV 89102
(702) 388-8899
(800) 216-5188
(702) 388-2966 (Fax)
✉nvpep@vegas.infi.net
http://www.nvpep.org

NEW HAMPSHIRE

Parent Information Center
Judith Raskin
P.O. Box 2405
Concord, NH 03302-2405
(603) 224-7005 (Voice & TDD)
(800) 232-0986 (in NH)
(603) 224-4379 (Fax)
✉picnh@aol.com
http://www.parentinformationcenter.org

NEW JERSEY

Statewide Parent Advocacy Network (SPAN)
Diana MTK Autin
35 Halsey Street, 4th Floor
Newark, NJ 07102
(973) 642-8100
(800) 654-SPAN
(973) 642-8080 (Fax)
✉span@spannj.org
http://www.spannj.org

NEW MEXICO

Parents Reaching Out
Larry Fuller
1920 "B" Columbia Drive SE
Albuquerque, NM 87106
(505) 247-0192
(505) 247-1345 (Fax)
✉nmproth@aol.com
http://www.parentsreachingout.org

EPICS Project
Martha Gorospe - Charlie
412 Camino Don Thomas, P.O. Box 788
Bernalillo, NM 87004-0788
(505) 867-3396
(800) 524-5176 (in NM)
(505) 867-3398 (Fax)
✉epics@swcr.org

NEW YORK

The Advocacy Center
Cassandra Archie
277 Alexander St., Suite 500
Rochester, NY 14607
(716) 546-1700
(800) 650-4967 (NY only)
(716) 546-7069 (Fax)
✉advocacy@frontiernet.net
http://www.advocacycenter.com
Statewide except for NY city.

Advocates for Children of NY
Ana Espada
151 West 30th Street, 5th Floor
New York, NY 10001
(212) 947-9779
(212) 947-9790 (Fax)
✉aespada@advocatesforchildren.org
http://www.advocatesforchildren.org
Five boroughs of New York City

Resources for Children with Special Needs, Inc.
Karen Schlesinger, Director
200 Park Ave. South, Suite 816
New York, NY 10003
(212) 677-4650
(212) 254-4070 (Fax)
✉info@resourcesnyc.org
http://www.resourcesnyc.org
New York City
(Bronx, Brooklyn, Manhattan, Queens, Staten Island)

NEW YORK (CPRC)

United We Stand
Lourdes Rivera-Putz
312 South 3rd Street
Brooklyn, NY 11211
(718) 302-4313, ext. 562
(718) 302-4315 (Fax)
✉uwsofny@aol.com
http://www.taalliance.org/ptis/uws/

NORTH CAROLINA

ECAC, Inc.
Connie Hawkins
907 Barra Row
Suites 102/103
Davidson, NC 28036
(704) 892-1321
(800) 962-6817 (NC only)
(704) 892-5028 (Fax)
✉ECAC1@aol.com
http://www.ecac-parentcenter.org/

Hope Network
Vickie Dieter
300 Enola Road
Margantown, NC 28655
(828) 433-2661
(828) 438-6457 (Fax)
✉vbdieter@abts.net

NORTH DAKOTA

ND Pathfinder Parent Training and Information Center
Kathryn Erickson
Arrowhead Shopping Center
1600 2nd Ave. SW, Suite 19
Minot, ND [illegible]1-3459
(701)837-75[illegible] (Voice)
(701) 837-7501 (TDD)
(800) 245-5840 (ND only)
(701) 837-7548 (Fax)
✉ndpath01@minot.ndak.net
http://www.pathfinder.minot.com

OHIO

Child Advocacy Center
Cathy Heizman
1821 Summit Road, Suite 303
Cincinnati, OH 45237
(513) 821-2400
(513) 821-2442 (Fax)
✉CADCenter@aol.com
Southwestern Ohio, Northern Kentucky, Dearborn County, Indiana

OCECD
Margaret Burley
Bank One Building
165 West Center St., Suite 302
Marion, OH 43302-3741
(740) 382-5452 (Voice & TDD)
(800)374-2806
(740) 383-6421 (Fax)
✉ocecd@gte.net
http://www.taalliance.org/PTIs/regohio/

OKLAHOMA

Oklahoma Parents Center, Inc.
Sharon Bishop
4600 Southeast 29th Street, Suite 115
Del City, OK 73115-4224
(405) 619-0500
(877) 553-IDEA
(405) 670-0776 (Fax)
✉okparentctr@aol.com

OREGON

Oregon COPE Project
Anne Brown
999 Locust St. NE
Salem, OR 97303
(503) 581-8156 (Voice & TDD)
(888) 505-COPE
(503) 391-0429 (Fax)
✉orcope@open.org
http://www.open.org/~orcope

PENNSYLVANIA (CPRC)

Hispanos Unidos para Niños Excepcionales
(Hispanics United for Exceptional Children)
Luz Hernandez
Buena Vista Plaza
166 W. Lehigh Ave., Suite 101
Philadelphia, PA 19133-3838
(215) 425-6203
(215) 425-6204 (Fax)
✉nuneinc@aol.com
City of Philadelphia, occasional service to surrounding counties

PENNSYLVANIA

Parent Education Network
Louise Thieme
2107 Industrial Hwy
York, PA 17402-2223
(717) 600-0100 (Voice & TDD)
(800) 522-5827 (in PA)
(800) 441-5028 (Spanish in PA)
(717) 600-8101 (Fax)
✉pen@parentednet.org
http://www.parentednet.org

The Mentor Parent Program
Gail Walker
P.O. Box 47
Pittsfield, PA 16340
(814) 563-3470
(814) 563-3445 (Fax)
✉gwalker@westpa.net

PUERTO RICO

APNI
Carmen Sellés deVilá
P.O. Box 21280
Ponce de Leon 724
San Juan, PR 00928-1301
(787) 763-4665
(800) 981-8492
(800) 949-4232
(787) 765-0345 (Fax)
✉apnipr@prtc.net
Island of Puerto Rico

RHODE ISLAND

RI Parent Information Network
Cheryl Collins
175 Main Street
Pawtucket, RI 02860
(401) 727-4144 (Voice)
(401) 727-4151 (TDD)
(800) 464-3399 (in RI)
(401) 727-4040 (Fax)
✉collins@ripin.org
http://www.ripin.org/

SOUTH CAROLINA (CPRC)

The Family Resource Center and
Parent Training & Resource Center
Beverly McCarty
MUSC - College of Health Professions, Research Office
19 Hagood Avenue - Suite 910
P.O. Box 250822
Charleston, SC 29425
(843) 792-3025
(843) 792-1107 (Fax)
✉mccartyb@musc.edu
Tri-county: Charleston, Berkeley, and Dorchester

SOUTH CAROLINA

PRO-PARENTS
Mary Faddy
652 Bush River Road
Suite 218
Columbia, SC 29210
(803) 772-5688 (Voice)
(800) 759-4776 (in SC)
(803) 772-5341 (Fax)
✉proparents@aol.com
http://community.columbiatoday.com/realcities/proparents

SOUTH DAKOTA

South Dakota Parent Connection
Lynn Boettcher Fjellanger
3701 West 49th St., Suite 200B
Sioux Falls, SD 57106
(605) 361-3171 (Voice & TDD)
(800) 640-4553 (in SD)
(605) 361-2928 (Fax)
✉lynnbf@sdparent.org
http://www.sdparent.org

TENNESSEE

The Arc of Davidson County
Norman Tenebaum
1207 17th Avenue South
Nashville, TN 37212
(615) 321-5699
(315) 322-9184 (Fax)
✉ntenebaum@aredc.org

Support and Training for Exceptional Parents, Inc. (STEP)
Nancy Diehl
424 E. Bernard Ave., Suite 3
Greeneville, TN 37745
(423) 639-0125 (Voice)
(423) 636-8217 (TDD)
(800) 280-STEP (in TN)
(423) 636-8217 (Fax)
✉tnstep@aol.com
http://www.tnstep.org

TEXAS (CPRC)

El Valle Community Parent Resource Center
Cindy Caballero
530 South Texas Blvd, Suite J
Weslaco, TX 78596
(956) 969-3611
(800) 680-0255 (TX only)
(956) 969-8761 (Fax)
✉texasfiestaedu@acnet.net
http://www.tfepoder.org
Cameron, Willacy, & Starr Counties.

The Arc of Texas in the Rio Grande Valley
Parents Supporting Parents Network
Leticia Padilla
601 N Texas Blvd
Weslaco, TX 78596
(956) 447-8408
(888) 857-8688
(956) 973-9503 (Fax)
✉padillal@earthlink.net
http://www.thearcoftexas.org

Partners Resource Network Inc.
Janice Meyer
1090 Longfellow Drive, Suite B
Beaumont, TX 77706-4819
(409) 898-4684 (Voice & TDD)
(800) 866-4726 (in TX)
(409) 898-4869 (Fax)
✉path@partnerstx.org
http://www.PartnersTX.org

Project PODER
Yvette Hinojosa
1017 N. Main Ave., Suite 207
San Antonio, TX 78212
(210) 222-2637
(800) 682-9747 (TX only)
(210) 475-9283 (Fax)
✉poder@tfepoder.org
http://www.tfepoder.org
San Antonio, Hondo, &
Castroville. Cameron, Hidalgo,
Willacy, & Starr Counties.

UTAH

Utah Parent Center
Helen Post
2290 East 4500 S., Suite 110
Salt Lake City, UT 84117-4428
(801)-272-1051
(800) 468-1160 (in UT)
(801) 272-8907 (Fax)
✉helenpo@utahparentcenter.org
http://www.utahparentcenter.org

VERMONT

Vermont Parent
Information Center
Connie Curtin
1 Mill Street, Suite A7
Burlington, VT 05401
(802) 658-5315 (Voice & TDD)
(800) 639-7170 (in VT)
(802) 658-5395 (Fax)
✉vpic@vtpic.com
http://www.vtpic.com

VIRGIN ISLANDS

Country/Hills Project
Catherine Rehema Glenn
#2 Nye Gade
St. Thomas USVI 00802
(340) 774-1662
(340) 774-1662 (Fax)
✉vifind@islands.vi
http://www.taalliance.org/
ptis/vifind/

VIRGIN ISLANDS

V.I. FIND
Catherine Rehema Glenn
#2 Nye Gade
St. Thomas, US VI 00802
(340) 774-1662
(340) 774-1662 (Fax)
✉vifind@islands.vi
http://www.taalliance.org/
ptis/vifind/

VIRGINIA (CPRC)

PADDA, Inc.
Mark Jacob
813 Forrest Drive, Suite 3
Newport News, VA 23606
(757) 591-9119
(888) 337-2332
(757) 591-8990 (Fax)
✉webmaster@padda.org
http://www.padda.org

VIRGINIA

Parent Educational Advocacy
Training Center
Cheri Takemoto
6320 Augusta Drive
Springfield, VA 22150
(703) 923-0010
(800) 869-6782 (VA only)
(703) 923-0030 (Fax)
✉partners@peatc.org
http://www.peatc.org

WASHINGTON

All Our Children
Paula Thorngate
34515 North Newport Highway
Chattaroy, WA 99003-9734
(509) 238-2198
(509) 464-8365 (Fax)
✉perdued@riversidesd.org.

WASHINGTON (CPRC)

Parent to Parent Power
Yvone Link
1118 S 142nd St.
Tacoma, WA 98444
(253) 531-2022
(253) 538-1126 (Fax)
✉yvone_link@yahoo.com

PAVE/STOMP
Heather Hebdon
6316 South 12th St., Suite B
Tacoma, WA 98465-1900
(253) 565-2266 (Voice & TDD)
(800) 572-7368
(253) 566-8052 (Fax)
✉hhebdon@washingtonpave.com
http://washingtonpave.org
U.S. Military installations; and as a resource for parent centers and others needing information on this subject.

Washington PAVE
Joanne Butts
6316 South 12th St., Suite B
Tacoma, WA 98465-1900
(253) -565-2266 (Voice & TDD)
(800) 572-7368 (in WA)
(253) 566-8052 (Fax)
✉jbutts@washingtonpave.com
http://www.washingtonpave.org

WEST VIRGINIA

West Virginia PTI
Pat Haberbosch
371 Broaddus Ave
Clarksburg, WV 26301
(304) 624-1436 (Voice & TDD)
(800) 281-1436 (in WV)
(304) 624-1438 (Fax)
✉wvpti@aol.com
http://www.wvpti.org

WISCONSIN

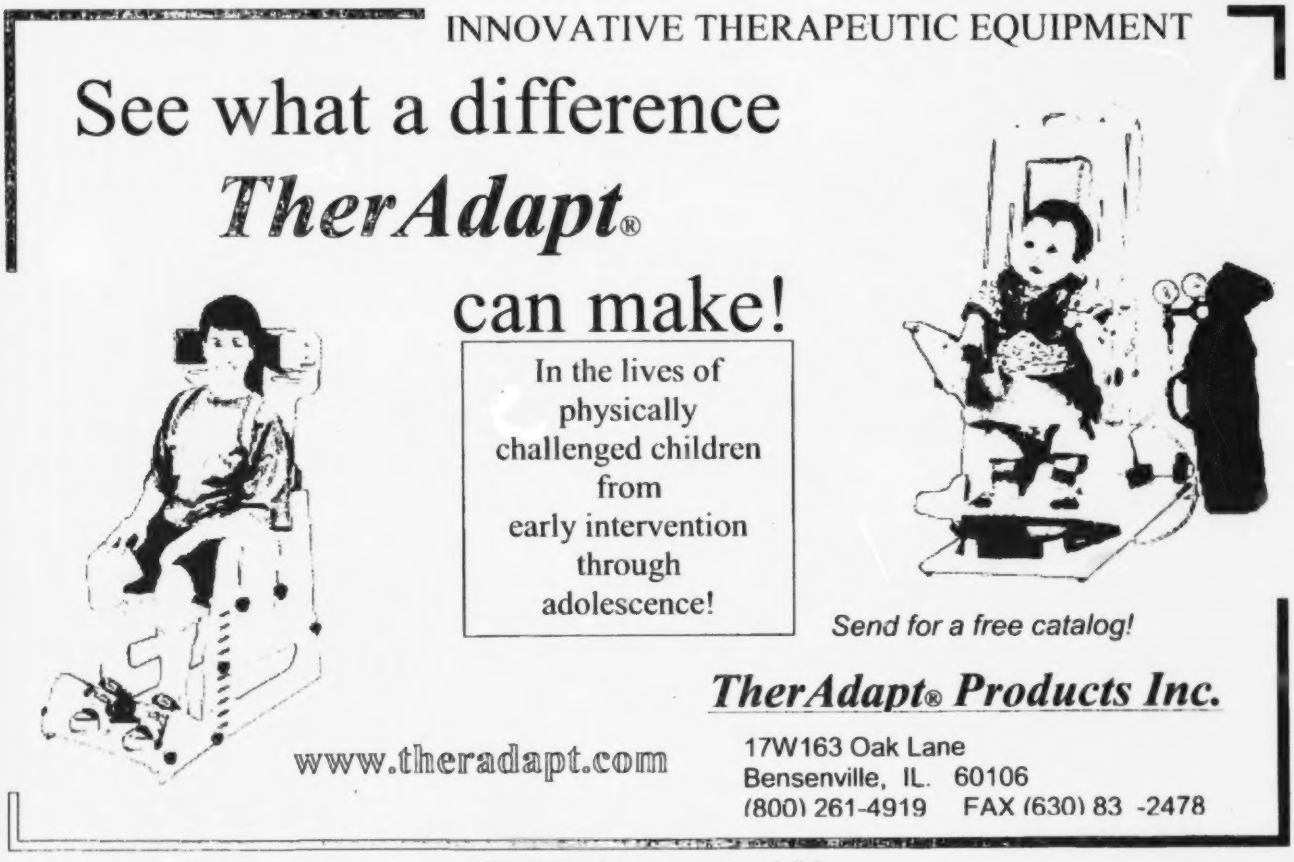
Native American Family
Empowerment Center
Don Rosin
Great Lakes Inter-Tribal Council, Inc.
2932 Highway 47N, P.O. Box 9
Lac du Flambeau, WI 54538
(715) 588-3324
(800) 472-7207 (WI only)
(715) 588-7900 (Fax)
✉drosin@newnorth.net

WISCONSIN (CPRC)

Wisconsin Family Assistance
Center for Education, Training
and Support
Janis M. Serak
2714 North Dr. Martin Luther
King Dr., Suite E
Milwaukee, WI 53212
(414) 374-4645
(414) 374-4635 (TTD)
(414) 374-4655 (Fax)
✉wifacets@execpc.com

WYOMING

Parent Information Center
Terri Dawson
5 North Lobban
Buffalo, WY 82834
(307) 684-2277 (Voice & TDD)
(800) 660-9742 (WY only)
(307) 684-5314 (Fax)
✉tdawson@wpic.org
http://www.wpic.org


INNOVATIVE THERAPEUTIC EQUIPMENT

See what a difference
TherAdapt®
can make!

In the lives of
physically
challenged children
from
early intervention
through
adolescence!

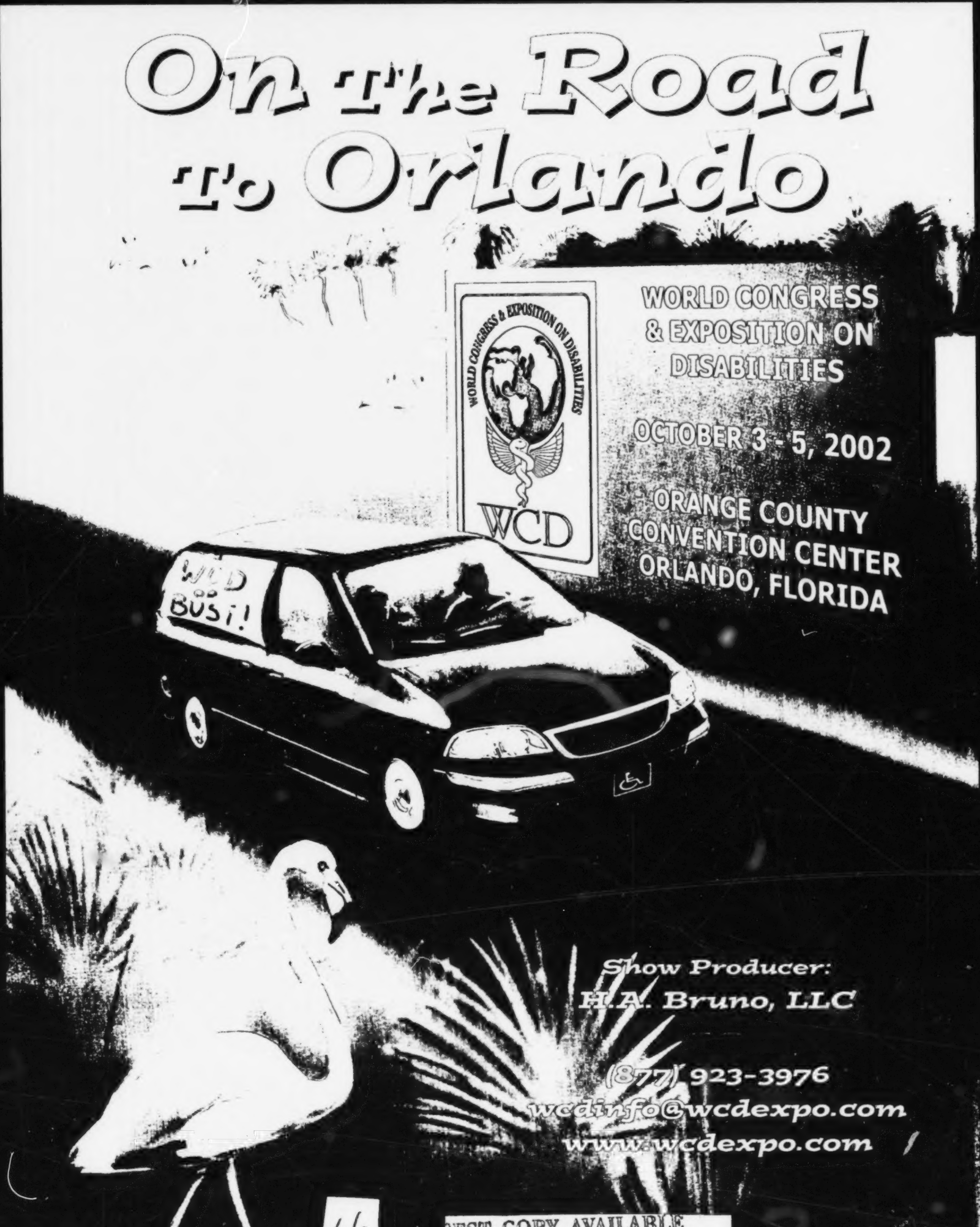
Send for a free catalog!

TherAdapt® Products Inc.
17W163 Oak Lane
Bensenville, IL. 60106
(800) 261-4919 FAX (630) 83 -2478

www.theradapt.com

Circle #128 or visit www.eparent.com/adinfo

65



On The Road To Orlando

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

OCTOBER 3 - 5, 2002

ORANGE COUNTY CONVENTION CENTER
ORLANDO, FLORIDA

Show Producer:
H.A. Bruno, LLC

(877) 923-3976
wcdinfo@wcdexpo.com
www.wcdexpo.com

Circle #141 or visit www.eparent.com/adinfo

66

BEST COPY AVAILABLE

Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

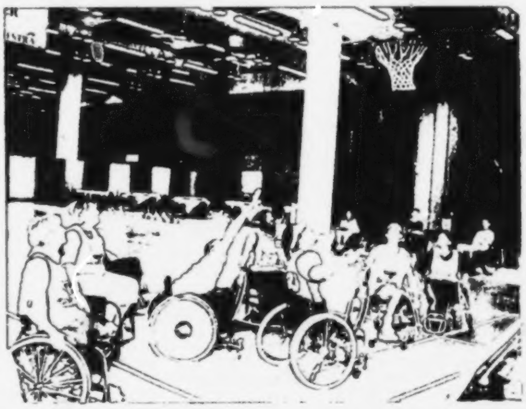
THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—October 3 - 5, 2002
LOCATION:
Orange County Convention Center—Orlando, Florida

A UNIQUE GATHERING— A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract

physicians ○ families ○ direct support professionals ○ people with disabilities ○ allied health care professionals ○ educators ○ adapted physical education specialists.

TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.



SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more.

EMPLOYMENT SYMPOSIUM PAVILION: Human resource managers will discuss career opportunities.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.

CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment.

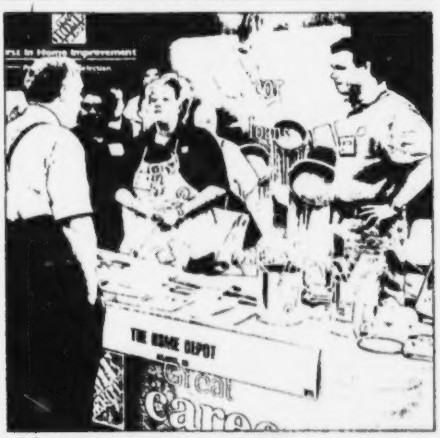
- All WCD attendees can experience discussions by internationally renowned experts specializing in neurology, orthopedics, pediatrics, internal medicine, family medicine, physical medicine, epidemiology, DDS, movement disorders, mitochondrial and metabolic disorders, neonatology, seizure disorders, autism, and other disabilities and chronic conditions as well as general practitioners.
- CME and CEU accreditation will be provided through approved accreditation institutions.
- Hear parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.
- An Employment Symposium produced in conjunction with the Florida Department of Education, Division of Vocational Rehabilitation Services will offer sessions for people with disabilities, their families and employers.
- Learn from special education professionals what is going on in classroom environments.
- Participate in adapted physical education activities and seminars.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

FOUNDING SPONSORS: ALLERGAN · sigma-tau PHARMACEUTICALS, INC. · EP Exceptional Parent

CONFERENCE SPONSOR: EP Foundation for Education, Inc.

October 3-5, 2002 ○ WORLD CONGRESS & EXPOSITION ON DISABILITIES



The Virtual WCD

The World Congress & Exposition on Disabilities (WCD) completed its second annual event on September 30, 2001. The owners and producers of the WCD felt they had an ongoing responsibility to ensure and facilitate a vibrant, effective marketplace and educational forum for the disability community. Therefore, as part of their commitment to provide the very best possible level of service and to broaden the scope to the widest possible audience, H.A. Bruno, LLC has invested much time, money and effort, in developing a strategic, internet-based event, known as the Virtual World Congress & Exposition on Disabilities (VWCD) (www.vwcdexpo.com).

H.A. Bruno has found a way to reach people with disabilities; their families; caregivers; physicians; nurses; therapists; general education, special education, physical education and adaptive physical education teachers, association members, and many other involved in the disability community. "In 2000, when we held our first event, we heard equally from attendees and exhibitors, 'Why don't you hold this show around the country?' It was just not feasible given the scope of the speakers and exhibitors. The way to reach around the country, and around the world, is through the internet," said William Schwaninger, VWCD director.

Nothing will ever replace the sight and feel of a real conference and exhibition, but for those not able to travel to and experience the WCD, the event is now within reach.

...for those not able to travel to and experience the WCD, the event is now within reach.

With over 240 VWCD exhibitors, attendees can view and then communicate easily with national and local organizations, service providers, the disability media, and manufacturers of products in over 50 industries without ever leaving their home or office. Even for those who were able to attend the WCD this year will now have the ability to keep up with the latest product developments; interact with exhibitors; read the latest in disability news; and learn from industry experts all year long—24 hours a day, seven days a week. The VWCD also has a comprehensive bulletin board which works as a conduit for people in similar situations to communicate. Facilities are in place to broadcast these messages to illicit the greatest number of responses. Future plans include chat rooms and seminars on-demand.

EP ("Exceptional Parent") magazine, through its web site (www.eparent.com), and VWCD will begin immediately working together to bring much needed information to the disability community. EPs educational content and reach will add an important element previously missing from the VWCD. Many non-profit associations and societies have already set up links to the VWCD and many more are soon expected to give their members easy access to the products and services VWCD has to offer.

The World Congress & Exposition on Disabilities has become the leading event for interdiscipline communications by offering a forum where professionals, children and adults with disabilities, their families and caregivers can meet, discuss and provide advice and support to each other. The Virtual WCD will now provide continued education and solutions as well as extend its reach throughout all segments of the disability community.

The WCD is organized by H.A. Bruno, LLC, a company whose senior management was previously associated with Blenheim Group, PLC, the world's largest trade show company and producer of more than 400 shows worldwide. The conference portion of the program is sponsored by the EP Foundation for Education, Inc., a 501(C)3 not-for-profit organization dedicated to improving the lives of people with disabilities, special health care needs and chronic conditions, and the families and others involved in their care and development. For more information on WCD, visit www.wcdexpo.com or call 877-WCD-EXPO.

Virtual WCD

www.vwcdexpo.com

- ☐ **View the latest products and services**
- ☐ **Read updated news items**
- ☐ **Communicate with people in the disability community**
- ☐ **Use the comprehensive bulletin board**

Everyone and anyone working with individuals with disabilities should attend this conference. It's a must!

Gloria Y. Stallworth, Human Services Senior Practitioner,
Wake Co. Human Services, Raleigh, NC

It was refreshing to see parents, doctors, therapists, classroom teachers and adapted physical educators all grouped together with a common interest.

R. R. Apache, Assistant Professor,
University of Nevada, Las Vegas, NV

The recent conference in Atlanta was a great experience. It was really helpful to see what other professionals in other states are doing. Overall the conference was excellent and I would encourage other professionals in my field to attend. I am planning to attend the WCD next year in Orlando.

Beverley Charles, an attendee, Mental Retardation
Developmental Administration, Washington, DC.

A great opportunity to learn from creative and inspirational adapted physical activity presenters.

Fiona Connor-Kuntz, APE Teacher, CH-UH Schools,
Cleveland Heights, OH

One word simply cannot sum up the experience. Try, AWESOME, WONDERFUL, INFORMATIVE, ORIGINAL, CREATIVE, EXCITING, INNOVATIVE AND EXTREMELY WELL ORGANIZED. The Muscular Dystrophy Family Foundation has been affiliated with the WCD from its conception. Whether you are a professional in the health care field, a parent, client, teacher, physical therapist, occupational therapist or a vendor, there is something for everyone to gain. And...the networking ability is outstanding! We are excited about the 2002 event and proud to be a supporting sponsor.

Judith R. Duncan, President/CEO,
Muscular Dystrophy Family Foundation,
Indianapolis, IN

Please send me information on the World Congress & Exposition on Disabilities, October 3-5, 2002

I AM INTERESTED IN: ☐ Exhibiting at the Show ☐ Attending the Show

Name

Company

Address

City State Zip Code

Telephone Fax

Email

Send Me Information:
877-923-3976, x832
Fax this page to:
201-226-1236
Mail this page back to:
WCD
210 Route 4 East
Suite 403
Paramus, NJ 07652
Email your request from:
www.wcdexpo.com

For complete details, visit our website at www.wcdexpo.com, or call: (877) 923-3976 ◦ (201) 226-1446

EP1/02

October 3-5, 2002 ◦ WORLD CONGRESS & EXPOSITION ON DISABILITIES

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

Authorized by federal legislation to help people with developmental disabilities and their families participate fully in their communities, University Centers for Excellence (UCEs) operate in academic settings to provide training, education, and direct services; conduct research; share information; and help consumers and their families find services. As a bridge between the academic world and the developmental disabilities service delivery system, UCEs work collaboratively with state agencies, their local affiliates, and various nongovernmental consumer-based organizations to build the capacity of communities to sustain all their citizens, including people with special needs.

Mental Retardation/Developmental Disabilities Research Centers (DDRCs), indicated by an (R) following the center name, are also included in this directory even though they are research–as opposed to direct service–facilities. These centers develop essential knowledge and information upon which to base new and improved treatments, supports, and services. Some of these research centers are housed at the same academic settings as the UCEs providing direct services. These listings were provided by the Association of University Centers on Disabilities, 8630 Fenton St., Ste. 410, Silver Spring, MD 20910; telephone: (301) 588-8252 (voice); (301) 588-3319 (TDD); fax: (301) 588-2842. Web site: http://www.aucd.org. When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the symbol, ✉. Web sites are listed with the standard http:// before each. (Unless otherwise indicated, telephone numbers are for voice only.)

ALABAMA

**Civitan International
Research Center**
The University of Alabama
at Birmingham
1719 Sixth Ave. South (Location)
CIRC 137, 1530 Third Avenue
South (Mailing Address)
Birmingham, AL 35294-0021
(205) 934-8900
(205) 975-6330 (fax)
✉sramey@uab.edu
http://www.circ.uab.edu

ALASKA

**Center for Human
Development, UAP**
University of Alaska Anchorage
2210 Arca Drive
Anchorage, AK 99508
(907-272-8270
(907)274-4802 (fax)
http://www.alaskachd.org

AMERICAN SAMOA

Pacific Basin Program
American Samoa
Community College
Pago Pago, AS 96799
(684) 699-9155
✉spgaleai@blueskynet.as

ARIZONA

Arizona UCD
Northern Arizona University
Institute for Human Development
PO Box 5630
Flagstaff, AZ 86011-5630
(928 -523-4791
(928) 523-1695 (TDD)
(928) 523-4791 (fax)
http://www.nau.edu/~ihd

ARKANSAS

**Partners for Inclusive
Communities**
2001 Pershing Circle, Suite 300
North Little Rock, AR 72114
(501)682-9908
(800) 831-4827
(501) 682-9902 (TDD)
(501) 682-9991 (fax)
http://www.uams.edu/uap

CALIFORNIA

**University Affiliated
Program, California**
University of California,
Los Angeles
Neuropsychiatric Institute
and Hospital
300 UCLA Medical Plaza,
Suite 3316
Los Angeles, CA 90095-6967
(310) 825-0170
(310) 794-1143 (fax)
✉oraynor@mednet.ucla.edu
http://uap.ucla.edu

**USC University
Affiliated Program, California**
California Childrens Hospital,
Los Angeles
P.O. Box 54700, MS #53
(5000 Sunset Blvd., 7th Floor)
Los Angeles, CA 90054-0700
(323) 669-2300
(323) 671-3842 (fax)
✉uscuap@chla.usc.edu
http://www.uscuap.org

COLORADO

JFK Partners
University of Colorado Health
Sciences Center
4200 E. 9th Ave. C221
Denver, CO 80262
(303) 864-5266
(303) 864-5267 (TDD)
(303) 864-5270 (fax)
✉jfkpartners@tchden.org
http://www.jfkpartners.org

CONNECTICUT

Connecticut UAP
University of Connecticut A.J.
Pappanikou Center for Excellence
in Developmental Disabilities
263 Farmington Ave., MC 6222
Farmington, CT 06030-6222
(860) 679-1500
(866) 623-1315
(860) 679-2242 (TDD)
(860) 679-1571 (fax)
✉bruder@nso1.uchc.edu
http://www.ajp.uconn.edu

DELAWARE

Center for Disabilities Studies
College of Human Services,
Education, and Public Policy
University of Delaware
166 Graham Hall
Newark, DE 19716
(302) 831-6974
(302) 831-4689 (TDD)
(302 -831-4690 (fax)
✉mgm@udel.edu
http://www.udel.edu/cds

DISTRICT OF COLUMBIA

Georgetown UCE
Georgetown University
Child Development Center
3307 M Street, NW
Suite 401
Washington, DC 200[illegible]-3935
(202) 687-8635
(202) 687-8899 (fax)
✉gucdc@georgetown.edu
http://www.georgetown.edu/gucdc

FLORIDA

**Mailman Center for Child
Development**
University of Miami School
of Medicine
Department of Pediatrics (D-820)
P.O. Box 016820
Miami, FL 33101
(305) 243-6801
(305) 243-5978 (TDD)
(305) 243-5978 (fax)
✉darmstrong@miami.edu
http://pediatrics.med.miami.edu/
mccd1.htm

GEORGIA

**Institute on Human Development
and Disability**
A University Affiliated Program
College of Family and Consumer
Sciences - The Univ. of Georgia
850 College Station Road River's
Crossing Building
Athens, GA 30602-4806
(706) 542-3457
(706) 542-6629 (TDD)
(706) 542-4815 (fax)
✉info@uap.uga.edu
http://www.uap.uga.edu

GUAM

**Guam Center for Excellence
in Developmental Disabilities
Education, Research**
University of Guam
Office of Academic Affairs
University of Guam
UOG Station
Mangilao, GU 96923
(671) 735-2481
(671) 734-6531 (TDD)
(671) 734-5709 (fax)
✉heidisan@uog.edu
http://uog2.uog.edu/uap

HAWAII

Center on Disability Studies
University of Hawaii at Manoa
University Center for Excellence
1776 University Avenue, UA 4-6
Honolulu, HI 96822
(808) 956-9199
(808) 956-5713 (fax)
✉huap@hawaii.edu
http://www.cds.hawaii.edu

IDAHO

University of Idaho UCE
Center on Disabilities and
Human Development
129 W. Third St.
Moscow, ID 83843
(208) 885-3559
(208) 885-3628 (fax)
✉jfodor@uidaho.edu
http://www.ets.uidaho.edu/cdhd

ILLINOIS

University of Illinois UCE
Institute on Disability and Human
Development (M/C 626)
Department of Disability and
Human Development
The Univ. of Illinois at Chicago
1640 West Roosevelt Road
Chicago, IL 60608-6904
(312) 413-1647
(312) 413-0453 (TDD)
(312) 413-1630 (fax)
http://www.uic.edu/depts/idhd

INDIANA

**Indiana Institute on Disability
and Community**
Indiana University
2853 East Tenth Street
Bloomington, IN 47408-2696
(812) 855-6508
(812) 855-9396 (TDD)
(812) 855-9630 (fax)
✉uap@indiana.edu
http://www.iidc.indiana.edu

Riley Child Development Center
Indiana University School of
Medicine, Section of Pediatrics
702 Barnhill Drive Room 5837
Indianapolis, IN 46202-5225
(317) 274-8167
(317)-274-9760 (fax)
✉mail@child-dev.com
http://www.child-dev.com

IOWA

**Iowa's University Center for
Excellence on Disabilities**
Center for Disabilities and
Development
100 Hawkins Drive
Iowa City, IA 52242-1011
(319) 356-1335
(319) 356-8284 (fax)
✉disABILITY-
RESOURCE@uiowa.edu
http://www.medicine.uiowa.edu/uhs/

KANSAS

University of Kansas/KU-UAP
Schiefelbusch Institute for Life
Span Studies
1052 Robert Dole Human
Development Center
Lawrence, KS 66045
(785)-864-4295
(785) 864-5323 (fax)
http//www.lsi.ukans.edu/lsi

KENTUCKY

University of Kentucky UCE
Interdisciplinary Human
Development Institute
Office of Research
University of Kentucky
126 Mineral Industries Building
Lexington, KY 40506-0051
(859) 257-1714
(859) 257-2903 (TDD)
(859) 323-1901 (fax)
http://www.ihdi.uky.edu

LOUISIANA

**Louisiana State University
Health Sciences Center**
Department of Child
& Family Services
Children's Center
3730 Blair Street
Shreveport, LA 71103
(318) 632-2030
(318) 632-2060 (fax)
✉cmitch@lsuhsc.edu
http://www.lsuhsc.edu/catalog/2
000/Allied Health/ChildrensCe

Louisiana UAP
Louisiana State University Health
Sciences Center
Human Development Center
1100 Florida Avenue
New Orleans, LA 70119-2799
(504) 942-8200
(504) 942-5900 (TDD)
(504) 942-8305 (fax)
✉hdcinfo@hdc.lsuhsc.edu
http://www.hdc.lsuhsc.edu

MAINE

**University Center for Excellence
in Developmental Disabilities
Education, Research and Service**
University of Maine
Center for Community Inclusion
5717 Corbett Hall
Orono, ME 04469-5717
(207) 581-1084
(800) 203-6957 (TDD)
(207) 581-1231 (fax)
✉CCIMAIL@umit.maine.edu
http://www.ume.maine.edu/cci/

70

MARYLAND

Kennedy Krieger Institute
707 North Broadway
Baltimore, MD 21205
(410) 502-9483
(410) 502-9806 (TDD)
(410) 502-9524 (fax)
http://www.kennedykrieger.org

MASSACHUSETTS

Eunice Kennedy Shriver Center
University of Massachusetts
Medical School
200 Trapelo Rd
Waltham, MA 02452-6319
(781) 642-0222
(800) 764-0200 (TDD)
(781) 642-0238 (fax)
✉Charles.Hamad@umassmed.edu
http://www.shriver.org/

Institute for Community Inclusion UCE
Childrens Hospital and University
of Massachusetts Boston
300 Longwood Avenue
Boston, MA 02115
(617) 355-6506
(617) 355-6956
(617) 355-7940 (fax)
✉ici@tch.harvard.edu
http://www.childrenshospital.org/ici

MICHIGAN

Developmental Disabilities Institute
Wayne State University
4809 Woodward Avenue
268 Leonard N. Simons Building
Detroit, MI 48202
(313) 577-2654
(313) 577-3770 (fax)
✉aa2732@wayne.edu
http://www.wayne.edu/DDI

MINNESOTA

Institute on Community Integration
University of Minnesota
College of Education and Human
Development
102 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455-0223
(612) 624-6300
(612) 624-9344 (fax)
✉info@icimail.coled.umn.edu
http://ici.umn.edu

MISSISSIPPI

Institute for Disability Studies: Mississippi's UCE
University of Southern Mississippi
Box 5163
Hattiesburg, MS 39406
(601) 266-5163
(888) 671-0051 (TDD)
(601) 266-5114 (fax)
✉Jane.Siders@usm.edu
http://www.ids.usm.edu

MISSOURI

UMKC Institute for Human Development (UAP)
2220 Holmes
Third Floor
Kansas City, MO 64108
(816) 235-1770
(800) 452-1185 (TDD)
(816) 235-1762 (fax)
✉ellerbuschk@umkc.edu
http://www.ihd.umkc.edu

NORTHERN MARIANA ISLANDS

Pacific Basin UAP/
Northern Marianas
Northern Marianas College
School of Education
PO Box 501250
As Terlaje Campus
Saipan, MP 96950
(670) 234-5498
(670) 235-3253 (fax)
http://www.nmcnet.edu/

MONTANA

The University of Montana Rural Institute:
Center of Excellence in
Developmental Disabilities
Education, Research & Service
52 Corbin Hall
634 Eddy Ave
Missoula, MT 59812-7056
(406) 243-5467
(800) 732-0323
(406) 243-5467 (TDD)
(406) 243-4730 (fax)
✉ruralinstitute@selway.umt.edu
http://ruralinstitute.umt.edu/

NEBRASKA

Nebraska UAP
Munroe-Meyer Institute for
Genetics and Rehabilitation
985450 Nebraska Medical Center
Omaha, NE 68198-5450
(402) 559-6430
(402) 559-5737 (fax)
✉mleibowi@unmc.edu
http://www.unmc.edu/mmi

NEVADA

Nevada UAP
University of Nevada, Reno
Research and Educational
Planning Center
MS/285
Reno, NV 89557
(775) 784-4921
(775) 784-4997 (fax)
http://www.unr.edu/repc/uappages/

NEW HAMPSHIRE

Institute on Disability UAP
University of New Hampshire,
Institute on Disabilty
University of New Hampshire
7 Leavitt Lane, Suite 101, UNH,
Durham, NH 03824-3595
Franklin Pierce Center for Health,
Law, and Ethics
Concord, NH 03301
(603) 862-4320
(603) 862-0555 (fax)
✉iod@unh.edu
http://www.iod.unh.edu

NEW JERSEY

The Elizabeth M. Boggs Center on Developmental Disabilities
University of Medicine
& Dentistry of New Jersey
Robert Wood Johnson
Medical School
335 George Street
P.O. Box 2688
New Brunswick, NJ 08903-2688
(732) 235-9300
(732) 235-9328 (TDD)
(732) 235-9330 (fax)
✉boggsweb@umdnj.edu
http://rwjms.umdnj.edu/
boggscenter

NEW MEXICO

University of New Mexico
Center for Development and
Disability Pediatrics
2300 Menaul Blvd., NE
Albuquerque, NM 87107
(505) 272-3000
(505) 272-0321 (TDD)
(505) 272-5280 (fax)
✉cdd@unm.edu
http://cdd.unm.edu

NEW YORK

Rose F. Kennedy University Center for Excellence in Developmental Disabilities Education, Research, and Service
Albert Einstein College of
Medicine
1410 Pelham Parkway South
Yeshiva University
Bronx, NY 10538
(718) 430-8523
(718) 904-1162 (fax)
✉0cerc@aecom.yu.edu
http://www.aecom.yu.edu/cerc/

Strong Center for Developmental Disabilities
University of Rochester
Strong Children's Hospital
601 Elmwood Avenue, Box 671
Rochester, NY 14642
(716) 275-0355
(716) 275-3366 (fax)
http://www.urmc.rochester.edu/st
rong/SCDD/

Westchester Institute for Human Development
Westchester Medical Center in
affiliation with New York Medical
College
Cedarwood Hall
Valhalla, NY 10595-1689
(914) 493-8204
(914) 493-1204 (TDD)
(914) 493-1973 (fax)
✉wihd@nymc.edu
http://www.nymc.edu/wihd

NORTH CAROLINA

Center for the Study of Development and Learning
University of North Carolina -
Chapel Hill
Campus Box 7255
Chapel Hill, NC 27599-7255
(919) 966-5171
(919) 966-2230 (fax)
http://www.cdl.unc.edu

NORTH DAKOTA

North Dakota Center for Persons with Disabilities
Minot State University
500 University Avenue West
Minot, ND 58707
(701) 858-3580;
(800) 233-1737
(701) 858-3580 (TDD)
(701) 858-3483 (fax)
✉ndcpd@farside.cc.misu.nodak.edu
http://www.ndcpd.org

OHIO

Nisonger Center UAP
The Ohio State University
1581 Dodd Drive
McCampbell Hall
Columbus, OH 43210-1296
(614) 247-7900
(614) 292-3727 (fax)
http://www.osu.edu/units/osunc/

University of Cincinnati UCE
Cincinnati Childrens Division of
Developmental Disabilities
(formerly Cincinnati
Center for DD)
Pavilion Building
3333 Burnet Avenue
Cincinnati, OH 45229-3039
(513) 636-4688
(513) 636-4626 (TDD)
(513)636-7361 (fax)
✉loppes0@chmcc.org
http://www.cincinnatichildrens.
org/Affiliates/74

OKLAHOMA

Center for Interdisciplinary Learning and Leadership
University of Oklahoma Medical
Center
College of Medicine
PO Box 26901, ROB 342
Oklahoma City, OK 73190-3042
(405) 271-4500
(800) 627-6827
(405) 271-1464 (TDD)
(405) 271-1459 (fax)
✉Valerie-Williams@ouhsc.edu
http://w3.ouhsc.edu/
ceddersoklahoma

OREGON

Center on Human Development
University of Oregon
College of Education
5252 University of Oregon
Eugene, OR 97403-5252
(541) 346-3591
(541) 346-5639 (fax)
✉uocedd@darkwing.uoregon.edu
http://darkwing.uoregon.edu/~uo
cedd/index.html

Oregon Institute on Disability & Development
Oregon Health Sciences University
Child Development and
Rehabilitation Center
PO Box 574
707 SW Gaines Road
Portland, OR 97207
(503) 494-8364
(503 -494-6868 (fax)
✉oidd@ohsu.edu
http://www.oidd.org

PENNSYLVANIA

Children's Seashore House of The Children's Hospital of Philadelphia
University of Pennsylvania
School of Medicine
3405 Civic Center Boulevard
Room 210
Philadelphia, PA 19104
(215) 590-7466
(215) 590-9339 (fax)
http://www.chop.edu

Institute on Disabilities/UCE
Temple University
423 Ritter Annex
13th & Cecil B. Moore Avenue
Philadelphia, PA 19122
(215) 204-1356
(215) 204-6336 (fax)
http://www.temple.edu/inst_disabilities

PUERTO RICO

Puerto Rico Institute on Developmental Disabilities/UAP
University of Puerto Rico
Graduate School of Public Health
Medical Sciences Campus
Box 345067
San Juan, PR 00936-5067
(787) 754-4377
(787) 764-5424 (fax)
✉mmendia@rcm.upr.edu

RHODE ISLAND

Rhode Island UAP
Rhode Island College
600 Mount Pleasant Avenue
Providence, RI 02908
(401) 456-8072
(401) 456-8773 (TDD)
(401) 456-8150 (fax)
http://www.uapri.org

SOUTH CAROLINA

University of South Carolina (A UCE)
Center for Disability Resources
Department of Pediatrics
School of Medicine
Columbia, SC 29208
(803) 935-5231
(803) 935-5059 (fax)
http://www.cdd.sc.edu

SOUTH DAKOTA

Center for Disabilities
The University of South Dakota
School of Medicine
Department of Pediatrics
1400 West 22nd Street
Sioux Falls, SD 57105-1570
(605) 357-1439
(800) 658-3080 Toll Free Number
(800) 658-3080 (TDD)
(605) 357-1438 (fax)
http://www.usd.edu/cd

TENNESSEE

Boling Center for Developmental Disabilities
University of Tennessee UCE
711 Jefferson Avenue
Memphis, TN 38105
(901)-448-6511
(901) 448-7097 (fax)
✉wwilson@utmem.edu
http://www.utmem.edu/bcdd/

MIND
Vanderbilt University
Child Development Center
2100 Pierce Avenue
Medical Center South, Room 404
Nashville, TN 37232-3573
(615) 936-1104
(615) 936-0256 (fax)
✉tokesha.warner@mcmail.
vanderbilt.edu
http://peds.mc.vanderbilt.edu/
cdc/MIND.html

TEXAS

Texas Center for Disability Studies
The University of Texas at Austin
College of Education
Sanchez Building, 252
D5100
Austin, TX 78712-1290
(512) 471-7621
(512) 471-1844 (TDD)
(512) 471-7549 (fax)
✉txcds@mail.utexas.edu
http://tcds.edb.utexas.edu/

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

UTAH

Center for Persons with Disabilities
A University Center for Excellence
Utah State University
6800 Old Main Hill
Logan, UT 84322-6800
(435) 797-1981
(866) 284-2821
(435)-797-1981 (TDD)
(435)-797-3944 (fax)
✉sharon@cpd2.usu.edu
http://www.cpd.usu.edu

VERMONT

Center on Disability and Community Inclusion
The UCE of Vermont/University of Vermont
College of Education
and Social Services
101 Cherry Street, Ste. 450
Burlington, VT 05401-4439
(802) 656-4031
(802) 656-4031 (TDD)
(802) 656-1357 (fax)
✉mcollins@zoo.uvm.edu
http://www.uvm.edu/~uapvt

VIRGIN ISLANDS

Virgin Islands UAP
University of the Virgin Islands
Office of the Provost and Senior
Vice President
2 John Brewers Bay
St.Thomas, VI 00803
(340) 693-1202
(340) 693-1205 (fax)
✉lragste@uvi.edu
http://www.uvi.edu/
pub-relations/viuapindx.htm

VIRGINIA

Virginia University Center for Excellence
Virginia Commonwealth
University
Virginia Institute for
Developmental Disabilities
PO Box 843020
700 E Franklin Street, 10th Floor
Richmond, VA 23284-3020
(804) 828-3876
(800) 828-1120 (TDD)
(804) 828-0042 (fax)
http://www.vcu.edu/vidd/

WASHINGTON

Center on Human Development and Disabilities
University of Washington
PO Box 357920
Seattle, WA 98195
(206) 543-2832
(206) 543-5771 (fax)
✉Chdd@uwashington.edu
http://www.depts.washington.edu/chdd

WEST VIRGINIA

West Virginia University
Center for Excellence in
Disabilities
WVUCED
955 Hartman Run Road
Morgantown, WV 26505
(304) 293-4692
(304) 293-7294 (fax)
✉wvuced@wvu.edu
http://www.ced.wvu.edu/

WISCONSIN

Waisman Center UAP
1500 Highland Ave
Madison, WI 53705
(608) 263-1656
(608) 263-0529 (fax)
http://www.waisman.wisc.edu/

WYOMING

Wyoming INstitute for Disabilities (WIND)
University of Wyoming
215 Ivinson Building
Laramie, WY 82071-4298
(307) 766-2761
(307) 766-2720 (TDD)
(307) 766-2763 (fax)
✉WIND.uw@uwyo.edu
http://wind.uwyo.edu/

Is my baby okay?

If you are worried about the way your baby crawls or sits, contact us. We have information that will help you talk to your baby's doctor about your concerns.

CALL NOW for a free brochure and other information.

1-800-955-2445

Pathways Awareness Foundation

200 E. Randolph Street
Chicago, IL 60601
Endorsed by the
American Academy of Pediatrics
Illinois Chapter
www.pathwaysawareness.org

Circle #68 or visit www.eparent.com/adinfo

72

ALLIANCE FOR TECHNOLOGY ACCESS CENTERS

The Alliance for Technology Access (ATA) began in 1987 as a joint project of a grassroots organization, the Disabled Children's Computer Group and a major corporation, Apple Computer™. From this small group of parents, consumers, and professionals, the ATA has grown into one of the nation's largest resources to help children and adults who have disabilities gain access to the benefits of assistive technology.

The Alliance for Technology Access (ATA) is a national network of Resource Centers, individual and organization Associate members and vendor members. All local nonprofit ATA Resource Centers are operated through a collaboration of people with disabilities, family members, and professionals in related fields. All are barrier-free in architecture as well as in attitude, and are committed to providing services, information and referral for everyone who contacts them. Associate members include a wide range of individuals and organizations who work in their own communities and ways to support our mission.

The mission of the Alliance for Technology Access is to connect children and adults with disabilities to technology tools. If you support this mission, we invite you to join us in realizing its potential.

By joining ATA you become a part of a vital nationwide network with the most up-to-date information about assistive technology. Stay on the cutting edge of the latest technological innovations, test and refine new products. Join others who are key players in the world of technology access.

To get more information about the Alliance for Technology Access (ATA) and/or how to become a member, contact the national office at (800) 455-7970 or visit the ATA Web site: http://www.ATAccess.org.

This listing was provided by the ATA (for the National Office, see below). Editor's Note: When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard http:// before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

Birmingham Alliance for Technology Access Center
Birmingham Independent Living Center
206 13th Street South
Birmingham, AL 35233-1317
(205) 251-2223 (Voice/TDD)
✉mikenorris@mindspring.net

Technology Assistance for Special Consumers
P.O. Box 443
915 Monroe Street
Huntsville, AL 35804
(256) 532-5996 (Voice/TDD)
✉tasc@traveller.com
http://tasc.ataccess.org

ARIZONA

Technology Access Center of Tucson (TACT)
4710 East 29th Street
P.O. Box 13178
Tucson, AZ 85732-3178
(520) 745-5588 x1265
✉tactaz@aol.com
http://www.ed.arizona.edu/tact/index.htm

ARKANSAS

Technology Resource Center
c/o Arkansas Easter Seal Society
3920 Woodland Heights Road
Little Rock, AR 72212-2495
(501) 227-3602
✉atrce@aol.com

CALIFORNIA

Team of Advocates for Special Kids
100 W. Cerritos Ave.
Anaheim, CA 92805
(714) 533-8275
✉taskca@yahoo.com
http://www.taskca.org

Center for Accessible Technology
2547 8th St., 12-A
Berkeley, CA 94710-2572
(510) 841-3224 (Voice/TDD)
✉info@cforat.org
http://www.cforat.org

Computer Access Center
6234 West 87th Street
Los Angeles, CA 90045
(310) 338-1597
✉cac@cac.org
http://www.cac.org

iTECH - Parents Helping Parents
3041 Olcott Street
Santa Clara, CA 95054-3222
(408) 727-5775
✉iTech@php.com
http://www.php.com

San Diego Assistive Technology Center
United Cerebral Palsy Association
6153 Fairmount Ave., Suite 150
San Diego, CA 92120
(858) 278-5420
✉ucpsdatc@pacbell.net

FLORIDA

CITE, Inc. - Center for Independence, Technology & Education
215 E. New Hampshire St.
Orlando, FL 32804
(407) 898-2483
✉citeinfo@cite-fl.com
http://www.icflorida.com/community/groups/cite/

GEORGIA

Tech-Able, Inc.
1114 Brett Drive, Suite 100
Conyers, GA 30094
(770) 922-6768
✉techable@bellsouth.net
http://www.techable.org/

HAWAII

Aloha Special Technology Access Center
710 Green St.
Honolulu, HI 96813
(808) 523-5547
✉astachi@yahoo.com
http://www.geocities.com/astachi/index.html

IDAHO

United Cerebral Palsy of Idaho, Inc.
5420 West Franklin Road, Suite A
Boise, ID 83705
(208) 377-8070
✉ucpidaho@aol.com
http://ucpidaho.ataccess.org

ILLINOIS

Technology Assisting All People with Disabilities (TAAD, Inc.)
1640 W. Roosevelt Road
Room 408
Chicago, IL 60608
(312) 421-3373
✉taadinc@yahoo.com
http://www.taadinc.org

Northern Illinois Center for Adaptive Technology
3615 Louisiana Road
Rockford, IL 61108-6195
(815) 229-2163
✉davegrass@earthlink.net
http://nicat.ataccess.org

INDIANA

Assistive Technology Training and Information Center
Attic: A Resource Center on Independent Living
3354 Pine Hill Dr.
P.O. Box 2441
Vincennes, IN 47591
(812) 88-0575 (Voice/TDD)
✉inattic1@aol.com
http://www.theattic.org

KANSAS

Technology Resource Solutions for People
1710 West Schilling Road
Salina, KS 67402-1160
(785) 827-9383
✉trspks@midusa.net
http://www.occk.com/trsp.htm

KENTUCKY

Bluegrass Technology Center
961 Beasley Street, STE 103A
Lexington, KY 40509-4120
(800) 209-7767 (KY)
(859) 294-4343
(859) 294-0704 (Fax)
✉office@bluegrass-tech.org
http://www.bluegrass-tech.org

Western Kentucky Assistive Technology Consortium (WKATC)
PO Box 266
1000 Whitnell Avenue
Murray, KY 42071
(270) 759-4233
✉wkatc@wk.net
http://www.kde.state.ky.us/oet/customer/at/

EnTech: Enabling Technologies of Kentuckiana
Louisville Free Public Library
301 York Street
Louisville, KY 40203-2257
(502) 574-1637
(800) 890-1840 (KY)
✉entech@iglou.com
http://www.kde.state.ky.us/oet/customer/at/

MARYLAND

Learning Independence Through Computers, Inc. (LINC)
1001 Eastern Avenue, 3rd floor
Baltimore, MD 21202
(410) 659-5462 (Voice)
(410) 659-5472 (Fax/TDD)
✉info@linc.org
http://www.linc.org

MICHIGAN

Michigan's Assistive Technology Resource
1023 S. US 27, Suite B31
St. Johns, MI 48879
(989) 224-0333 (Voice or TDD)
(800) 274-7426 (MI)
(Voice or TDD)
(989) 224-0330 (Fax)
✉matr@match.org
http://www.matr.org

MINNESOTA

Simon Technology Center
Pacer Center
8161 Normandale Blvd.
Minneapolis, MN 55437-1044
(952) 838-9000 (Voice/TDD)

MONTANA

Parents, Let's Unite for Kids (PLUK)
516 N 32nd St
Billings, MT 59101
(406) 255-0540
(800) 222-7585 (MT)
✉plukinfo@pluk.org
http://www.pluk.org

NEW JERSEY

TECH Connection
Assistive Technology Solutions
c/o Family Resource Associates, Inc.
35 Haddon Avenue
Shrewsbury, NJ 07702-4007
(732) 747-5310
✉tecconn@aol.com
http://www.techconnection.org/

Center for Enabling Technology
622 Route 10 West, Suite 22B
Whippany, NJ 07981-0272
(973) 428.1455 (Voice)
(973) 428.1450 (TDD)
✉cetnj@aol.com
http://cetnj.ataccess.org/

NEW YORK

Techspress Resource Center for Independent Living
P.O. Box 210
401-409 Columbia Street, P.O. Box 210
Utica, NY 13503-0210
(315) 797-4642
✉rose.roberts@rcil.com

NORTH CAROLINA

Carolina Computer Access Center
Metro School
700 East Second Street
Charlotte, NC 28202-2826
(704) 342-3004
✉ccacnc@aol.com
http://ccac.ataccess.org

OHIO

Technology Resource Center
Job Mall
1133 Edwin C. Moses Blvd.
Suite 370
Dayton, OH 45408
(937) 461-3305
✉trcdoh@aol.com

RHODE ISLAND

TechACCESS Center of Rhode Island
110 Jefferson Blvd.
Warwick, RI 02888
(401) 463-0202 (Voice/TDD)
(800) 916-TECH (RI)
✉techaccess@techaccess-ri.org
http://users.ids.net/~taofri/tahome.html

TENNESSEE

Signal Center's Assistive Technology Center
109 North Germantown Road
Chattanooga, TN 37411
(423) 698-8528 x242
✉littleton@signal.chattanooga.net
http://www.signalcenters.com/Locations/Chattanooga/chattanooga.html

East Tennessee Technology Access Center, Inc.
4918 North Broadway
Knoxville, TN 37918
(865) 219-0130 (Voice/TDD)
(865) 219-0137 (Fax)
✉etstactn@aol.com
http://www.kornet.org/ettac/

Wheelchair Getaways®

The Leader in Accessible Van Rentals

- Long/Short Term Rentals
- 24-hr. Emergency Assistance
- Pick-Up and Delivery
- Full-size and Mini-Vans

Connecting People and Places...

Rent one of our vans today for:
* Vacations
* Sporting Events
* Medical Visits
* Replacement Vehicle
* Drive Before You Buy

Nationwide Reservations:
1-800-642-2042
www.wheelchairgetaways.com

Circle #137 or visit www.eparent.com/adinfo

ALLIANCE FOR TECHNOLOGY ACCESS CENTERS

West Tennessee Special Technology Access Resource Center (STAR)
60 Lynoak Cove
Jackson, TN 38305
(901) 668-3888
(800) 464-5619
✉infostar@starcenter.tn.org
http://www.starcenter.tn.org

Mid-South Access Center for Technology
University of Memphis
College of Education
Ball Hall Rm. 307B
Memphis, TN 38152
(901) 678-3919
✉kanderso@memphis.edu
http://www.people.memphis.edu/~coe_act/

Technology Access Center of Middle Tennessee
Fountain Square, Suite 126
2222 Metrocenter Blvd.
Nashville, TN 37228
(615) 248-6733 (Voice/TDD)
(800) 368-4651
✉techaccess@mindstate.com
http://tac.ataccess.org

UTAH

The Computer Center for Citizens with Disabilities
c/o Utah Center for Assistive Technology
1595 West 500 South
Salt Lake City, UT 84104
(801) 887-9500 (Voice/TDD)
✉cboogaar@usor.state.ut.us
http://www.usor.state.ut.us/ucat/computers.htm

VIRGIN ISLANDS

Virgin Islands Resource Center for the Disabled, Inc.
P.O. Box 308427
St. Thomas, VI 00803-8427
(340) 777-2253
✉vircd@islands.vi

VIRGINIA

Tidewater Center for Technology Access
1413 Laskin Road
Virginia Beach, VA 23451
(757) 437-6542 (Voice/TDD)
✉tcta@aol.com
http://tcta.ataccess.org

Berkshire Meadows

Nestled in the serene beauty of Western Massachusetts' Berkshire Hills, Berkshire Meadows offers a comprehensive, integrated year-round residential program for children, adolescents and young adults who are severely developmentally delayed and may be multiply disabled.

We help our population become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement, and support. We believe that all people, no matter how severe their disabilities, should be given the opportunity to achieve their maximum potential.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523, Ext. 14
berkshiremeadows.org

Circle #28 or visit www.eparent.com/adinfo

STATE ASSISTIVE TECHNOLOGY PROGRAMS

The following state assistive technology programs are funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under the Assistive Technology Act of 1998 (P.L. 105-394). The Assistive Technology Act of 1998 provides federal support for a nationwide program of grants to states to help individuals with disabilities obtain access to and funding for assistive technology devices and services. There are 56 state assistive technology projects, one located in each of the 50 states, the District of Columbia, American Samoa, Guam, the Commonwealth of the Northern Marianas, Puerto Rico, and the U.S. Virgin Islands.

Among other services, the Assistive Technology Act allows states to help individuals learn more about the many ways assistive technology can help them live, work, and learn more independently.

Depending on priorities in the states, the projects may provide the following regarding assistive technology devices and services:

- Information and referral
- Regional centers, demonstration centers
- Funding and policy information
- Training and technical assistance
- Financial loan programs
- Equipment recycling programs, device lending libraries

For more information, contact: RESNA Technical Assistance Project, 1700 N. Moore St., Ste. 1540, Arlington, VA 22209-1903; (703) 524-6686 (voice); (703) 524-6630 (TDD); (703) 524-6630 (fax); E-mail: resnata@resna.org. You may also wish to check out the project's Web site: http://www.resna.org/taproject.

Contact your state assistive technology program for more information. E-mail addresses are indicated by the symbol ✉. (Unless otherwise indicated, telephone numbers are for voice only.)

States Funded Under the Assistive Technology Act of 1998 and Administered by the NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH:

ALABAMA

ALABAMA STATEWIDE TECHNOLOGY ACCESS AND RESPONSE PROJECT (STAR) SYSTEM FOR ALABAMIANS WITH DISABILITIES
2125 East South Boulevard
P.O. Box 20752
Montgomery, AL 36120-0752
Project Director: Ted Bridges
Phone: (334) 613-3480
Phone: (800) STAR656 (In-State)
TTY: (334) 613-3519
FAX: (334) 613-3485
✉tbridges@rehab.state.al.us
Homepage:
http://www.rehab.state.al.us/star

ALASKA

ALASKA DIVISION OF VOCATIONAL REHABILITATION ASSISTIVE TECHNOLOGY PROGRAM
1016 West 6th Ave., Suite 205
Anchorage, AK 99501
Project Director: Jim Beck
Phone: (907) 269-3569
TTY: (907) 269-3570
FAX: (907) 269-3632
✉james_beck@labor.state.ak.us
Homepage:
http://www.labor.state.ak.us/at/index.htm

AMERICAN SAMOA

ASSISTIVE TECHNOLOGY SERVICE PROJECT (ASATS)
Division of Vocational Rehabilitation
Department of Human Resources
Pago Pago, American Samoa 96799
Project Director: Edmund Pereira
Phone: (684) 699-1529
TTY:(684) 233-7874
FAX:(684) 699-1376
✉EdPerei@yahoo.com

ARIZONA

ARIZONA TECHNOLOGY ACCESS PROGRAM (AZTAP)
Northern Arizona University
4105 N. 20th Street, Suite 260
Phoenix, AZ 85016
Project Director: Jill Oberstein
Phone: (602) 728- 9534
Phone: (800) 477-9921
TTY: (602) 728-9536
FAX: (602) 728-9535
✉jill.oberstein@nau.edu
Homepage:
http://www.nau.edu/ihd/aztap

ARKANSAS

ARKANSAS INCREASING CAPABILITIES ACCESS NETWORK (ICAN)
Arkansas Dept. of Workforce Education
Arkansas Rehabilitation Services
2201 Brookwood Drive, Suite 117
Little Rock, AR 72202
Project Director: Sue Gaskin
Phone/TTY: (501) 666-8868
Phone/TTY: (800) 828-2799 (In-State)
FAX: (501) 666-5319
✉sogaskin@ars.state.ar.us
Homepage: http://www.arkansas-ican.org

CALIFORNIA

CALIFORNIA ASSISTIVE TECHNOLOGY SYSTEM (CATS)
California Department of Rehabilitation
2000 Evergreen
Sacramento, CA 95815
Mailing Address:
P.O. Box 944222
Sacramento, CA 94244-2220
Information and Referral:
Colin Corby
Project Director: Dennis Law
Phone: (916) 263-8687
TTY: (916) 263-8685
FAX: (916) 263-8683
✉dorcats@dor.ca.gov
Homepage: http://www.atnet.org

COLORADO

ASSISTIVE TECHNOLOGY PARTNERS
1245 E. Colifax Ave., Suite 200
Denver, CO 80218
Project Director: Cathy Bodine
Phone: (303) 315-1280
TTY: (303) 837-8964
FAX: (303) 837-1208
✉cathy.bodine@uchsc.edu
Homepage:
http://www.uchsc.edu/atp

CONNECTICUT

CONNECTICUT ASSISTIVE TECHNOLOGY PROJECT
Department of Social Services, BRS
25 Sigourney St., 11th Floor
Hartford, CT 06106
Project Director: John M. Ficarro
Phone: (860) 424-4881
Phone: (800) 537-2549 (In-State)
TTY: (860) 424-4839
FAX: (860) 424-4850
✉cttap@aol.com
Homepage:
http://www.techact.uconn.edu

DELAWARE

DELAWARE ASSISTIVE TECHNOLOGY INITIATIVE (DATI)
Center for Applied Science & Engineering
University of Delaware/duPont Hospital for Children
1600 Rockland Road
P.O. Box 269
Wilmington, DE 19899-0269
Director: Beth A. Mineo Mollica, Ph.D.
Phone: (302) 651-6790
Phone: (800) 870 DATI (In-State)
TTY: (302) 651-6794
FAX: (302) 651-6793
✉dati@asel.udel.edu
Homepage:
http://www.asel.udel.edu/dati/

DISTRICT OF COLUMBIA

UNIVERSITY LEGAL SERVICES AT PROGRAM FOR THE DISTRICT OF COLUMBIA
300 I Street, NE, Suite 200
Washington, DC 20002
Program Manager: Alicia C. Johns
Phone: (202) 547-0198
TTY: (202) 547-2657
Fax: (202) 547-2662
✉ajohns@uls-dc.com
Homepage: http://www.atpdc.org

FLORIDA

FLORIDA ALLIANCE FOR ASSISTIVE SERVICE AND TECHNOLOGY (FAAST, Inc.)
1020 E. Lafayette St., Suite 110
Tallahassee, FL 32301-4546
Project Director: Terry Ward, Ph.D., ATP
Phone: (850) 487-3278 (V/TTY)
(850) 922-5951 (TTY)
(850) 487-2805 (FAX/TTY)
✉faast@faast.org
Homepage: http://faast.org

GEORGIA

GEORGIA TOOLS FOR LIFE
Department of Labor
Vocational Rehabilitation Program
1700 Century Center, Suite 300
Atlanta, GA 30345
Project Manager: Christopher Lee
Phone: (404) 638-0384
Phone: (800) 497-8665 (In-State)
TTY: (404) 657-3085
FAX: (404) 638-0388
✉toolsforlife@mindspring.com
Homepage: http://www.gatfl.org

GUAM

GUAM SYSTEM FOR ASSISTIVE TECHNOLOGY (GSAT)
University Affiliated Program-Developmental Disabilities
University of Guam, UOG Station
303 University Drive, Hse # 19
Dean Circle
Mangilao, Guam 96923
Principal Investigator: Heidi E. Farra-San Nicolas, Ph.D.
Acting Project Director:
June Quitugua
Phone: (671) 735-2490
TTY: (671) 734-8378
FAX: (671) 734-5709
✉gsat@ite.net
Homepage:
http://uog2.uog.edu/uap/gsat.html

HAWAII

ASSISTIVE TECHNOLOGY RESOURCE CENTERS OF HAWAII (ATRC)
414 Kuwili Street, Suite 104
Honolulu, HI 96817
Outreach Specialist:
Kimberly Shiraishi
Project Director: Barbara Fischlowitz-Leong
Phone: (808) 532-7110 (V/TTY)
Phone: (800) 645-3007 (V/TTY, In-State)
FAX: (808) 532-7120
✉atrc@atrc.org
Homepage: http://www.atrc.org

IDAHO

IDAHO ASSISTIVE TECHNOLOGY PROJECT
129 W. Third Street
Moscow, ID 83844-4401
Information and Specialist: Susan House, Phone: (208) 885-3771
Project Director: Ron Seiler
Phone: (208) 885-3559 (V/TTY)
FAX: (208) 885-3628
✉seile861@uidaho.edu
Homepage:
http://www.ets.uidaho.edu

ILLINOIS

ILLINOIS ASSISTIVE TECHNOLOGY PROJECT
1 W. Old State Capitol Plaza
Suite 100
Springfield, IL 62701
Project Director:
Wilhelmina Gunther
Phone: (217) 522-7985
TTY: (217) 522-9966
FAX: (217) 522-8067
✉iatp@iltech.org
Homepage: http://www.iltech.org

INDIANA

ASSISTIVE TECHNOLOGY THROUGH AWARENESS IN INDIANA
ATTAIN PROJECT
2346 Lynhurst Drive
Airport Office Center, Suite 507
Indianapolis, IN 46241
Project Director: Cris Fulford
Phone: (317) 486-8808
Phone: (800) 528-8246 (In-State)
TTY: (800) 486-8809 (National)
FAX: (317) 486-8809
✉attain@attaininc.org
Homepage:
http://www.attaininc.org

IOWA

IOWA PROGRAM FOR ASSISTIVE TECHNOLOGY (IPAT)
Iowa's University Center for Excellence in Disabilities, Center for Disabilities & Development
100 Hawkins Drive, Rm S295
Iowa City, IA 52242-1011
Information and Referral:
Ann Dudler
Phone: (319) 356-0766
Director: Jane Gay
(319) 356-4463
Phone: (800) 331-3027
TTY: (877) 686-0032
FAX: (319) 356-8284
✉Infotech@uiowa.edu
Homepage
http://www.uiowa.edu/infotech

KANSAS

ASSISTIVE TECHNOLOGY FOR KANSANS PROJECT
2601 Gabriel
Parsons, KS 67357
Project Director: Charles R. Spellman
Phone: (620) 421-6550 ext. 1890
✉spellman@ku.edu
Co-Director: Sara Sack
Project Coordinator:
Sheila Simmons
Phone/TTY: (620) 421-8367
Phone: (800) KAN DO IT
FAX/TTY: (620) 421-0954
✉ssack@ku.edu
Homepage:
http://www.atk.lsi.ukans.edu

STATE ASSISTIVE TECHNOLOGY PROGRAMS

KENTUCKY

KENTUCKY ASSISTIVE TECHNOLOGY SERVICE (KATS) NETWORK
Charles McDowell
Rehabilitation Center
8412 Westport Road
Louisville, KY 40242
Information and Referral:
Ronji Dearborn
Project Director: J. Chase
Forrester, J.D.
Phone: (502) 327-0022
Phone: (800) 327-5287
(V/TTY, In-State)
FAX: (502) 327-9974
TTY: (502) 327-9855
✉katsnet@iglou.com
Homepage:
http://www.katsnet.org

LOUISIANA

LOUISIANA ASSISTIVE TECHNOLOGY ACCESS NETWORK (LATAN)
P.O. Box 14115
Baton Rouge, LA 70898-4115
Executive Director: Julie Nesbit
Phone: (225) 925-9500 (V/TTY)
Phone: (800) 270-6185 (V/TTY)
FAX: (225) 925-9560
✉jnesbit@latan.org
Homepage: http://www.latan.org

MAINE

MAINE CONSUMER INFORMATION AND TECHNOLOGY TRAINING EXCHANGE (CITE)
Maine CITE Coordinating Center
University of Maine
System Network
46 University Drive
Augusta, ME 04330
Project Director: Kathy Powers
Phone: (207) 621-3195
TTY: (207) 621-3482
FAX: (207) 621-3193
✉kpowers@maine.edu
Homepage:
http://www.mainecite.org

MARYLAND

MARYLAND TECHNOLOGY ASSISTANCE PROGRAM (TAP)
Governor's Office for
Individuals with Disabilities
2301 Argonne Drive
RM T17
Baltimore, MD 21218
Information Specialist: Patrick
McCurdy
Project Director: Paul Rasinski
Phone: (800) 832-4827
Phone: (410) 554-9230 (V/TTY)
FAX: (410) 554-9237
✉rasinski@mdtap.org
Homepage:
http://www.mdtap.org

MASSACHUSETTS

MASSACHUSETTS ASSISTIVE TECHNOLOGY PARTNERSHIP (MATP)
MATP Center
Children's Hospital
1295 Boylston Street, Suite 310
Boston, MA 02215
Project Director: Marylyn Howe
Phone: (617) 355-7820 (V)
Phone: (800) 848-8867
(V/TTY, In-State)
Phone: (617) 355-7301
TTY: (617) 355-7301
FAX: (617) 355-6345
✉matp@matp.org
Homepage: http://www.matp.org

MICHIGAN

MICHIGAN TECH 2000
Michigan Assistive
Technology Project
740 W. Lake Lansing Rd.,
Suite 400
East Lansing, MI 48823
Project Director: Kathryn Wyeth
Phone: (517) 333-2477 (V/TDD)
Phone: (800) 760-4600 (In-State)
FAX: (517) 333-2677
✉kdwyeth@match.org
Homepage:
http://www.copower.org

MINNESOTA

MINNESOTA STAR PROGRAM
300 Centennial Building
658 Cedar Street
St. Paul, MN 55155
Executive Director: Mary Brogdon
Phone: (800) 657-3862 (V)
(In-Stat
Phone: (800) 657-3895
(TTY In-State)
Phone: (651) 296-2771
TTY: (651) 296-8478
FAX: (651) 282-6671
✉star.program@state.mn.us
Homepage:
http://www.admin.state.mn.us/

MISSISSIPPI

MISSISSIPPI PROJECT START
P.O. Box 1698
Jackson, MS 39215-1000
Phone: (601) 987-4872
Project Director: Stephen Power
Phone: (601) 987-4872
Phone: (800) 852-8328
(V/TTY In-State)
FAX: (601) 364-2349
✉spower@mdrs.state.ms.us

MISSOURI

MISSOURI ASSISTIVE TECHNOLOGY PROJECT
4731 South Cochise, Suite 114
Independence, MO 64055-6975
Project Director: Diane Golden, Ph.D.
Phone: (800) 647-8557 (In-State)
TTY: (800) 647-8558
Phone: (816) 373-5193
TTY: (816) 373-9315 (In-State)
FAX: (816) 373-9314
✉matpmo@swbwll.net
Homepage:
http://www.dolir.state.mo.us/matp/

MONTANA

MONTECH
Rural Institute on Disabilities
The University of Montana
634 Eddy Avenue
Missoula, MT 59812
Project Director: Gail McGregor
TTY: (800) 732-0323 (National)
Phone: (406) 243-5676
FAX: (406) 243-4730
✉montech@selway.umt.edu
Homepage:
http://rudi.montech.umt.edu/

NEBRASKA

NEBRASKA ASSISTIVE TECHNOLOGY PARTNERSHIP
5143 South 48th Street, Suite C
Lincoln, NE 68516-2204
Information and Referral:
Kathryn Kruse
Project Director: Mark Schultz
Phone: (888) 806-6287
(V/TTY In-State)
Phone: (402) 471-0734 (V/TTY)
FAX: (402) 471-6052
✉mschultz@atp.state.ne.us
Homepage:
http://www.atp.state.ne.us

NEVADA

NEVADA ASSISTIVE TECHNOLOGY COLLABORATIVE
Rehabilitation Division
Community Based Services
711 South Stewart Street
Carson City, NV 89710
Project Administrator:
Donny Loux
Phone: (775) 687-4452
TTY: (775) 687-3388
FAX: (775) 687-3292
✉pdgowins@nvdetr.org
Homepage:
http://www.state.nv.us 80

NEW HAMPSHIRE

NEW HAMPSHIRE TECHNOLOGY PARTNERSHIP PROJECT
Institute on Disability
The Concord Center
Ten Ferry Street #14
Concord, NH 03301
Project Director: Jan Nisbet, Ph.D.
Phone: (603) 862-4320
Project Coordinator:
Sonke Dornblut
Phone: (603) 224-0630
Phone/TTY: (603) 224-0630
Phone: (800) 427-3338
(V/TTY In-State)
FAX: (603) 226-0389
✉sonke.dornblut@unh.edu
Homepage:
http://www.iod.unh.edu/projects/
assist.htm

NEW JERSEY

TECHNOLOGY ASSISTIVE RESOURCE PROGRAM (TARP)
New Jersey Protection and
Advocacy, Inc.
210 South Broad Street, 3rd Floor
Trenton, NJ 08608
Project Director: Ellen Lence
Phone: (609) 292-9742
Phone: (800) 342-5832 (In-State)
TTY: (609) 633-7106
FAX: (609) 777-0187
✉rringh@njpanda.org
Homepage:
http://www.njpanda.org

NEW MEXICO

NEW MEXICO TECHNOLOGY ASSISTANCE PROGRAM
435 St. Michael's Drive, Building D
Santa Fe, NM 87505
Project Director: Alan Klaus
Phone: (800) 866-2253
Phone: (505) 954-8539 (TDD)
FAX: (505) 954-8562
✉aklaus@state.nm.us
Homepage:
http://www.nmtap.com

NEW YORK

NEW YORK STATE TRAID PROJECT
NYS Office of Advocate for
Persons with Disabilities
One Empire State Plaza,
Suite 1001
Albany, NY 12223-1150
Project Manager: Lisa Rosano-
Kaczkowski
Phone: (518) 474-2825
Phone: (800) 522-4369 (V/TDD,
In-State)
TDD: (518) 473-4231
FAX: (518) 473-6005
✉traid@emi.com
Homepage:
http://www.advoc4disabled.
state.ny.us/
TRAID_Project/technlog.htm

NORTH CAROLINA

NORTH CAROLINA ASSISTIVE TECHNOLOGY PROJECT
Department of Health
and Human Services
Division of Vocational
Rehabilitation Services
1110 Navaho Drive, Suite 101
Raleigh, NC 27609-7322
Project Director: Ricki Hiatt
Phone/TTY: (919) 850-2787
FAX: (919) 850-2792
✉ncatp@mindspring.com
Homepage: http://www.
mindspring.com/~ncatp

NORTH DAKOTA

NORTH DAKOTA INTERAGENCY PROGRAM FOR ASSISTIVE TECHNOLOGY (IPAT)
P.O. Box 743
Cavalier, ND 58220
Director: Judie Lee
Phone/TTY: (701) 265-4807
FAX: (701) 265-3150
✉jlee@polarcomm.com
Homepage:
http://www.ndipat.org

MARIANA ISLANDS

COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS ASSISTIVE TECHNOLOGY PROJECT
Governor's Developmental
Disabilities Council, Systems of
Technology-Related Assistance for
Individuals with Disabilities
P.O. Box 502565 CK
Saipan, MP 96950-2565
Project Director: Thomas J.
Camacho
Phone/TTY: (670) 664-7005/6
FAX: (670) 664-7010
✉straid@cnmiddcouncil.org
Homepage: http://www.
cnmiddcouncil.org

OHIO

ASSISTIVE TECHNOLOGY OF OHIO
J.L. Camera Center
2050 Kenny Road, 9th Floor
Columbus, OH 43212
Executive Director: Douglas Huntt
Associate Director: Bill Darling
Phone: (614) 292-3158
✉darling.12@osu.edu
Phone/TTY: (614) 292-2426
Phone/TTY: (800) 784-3425
(In-State)
TTY: (614) 292-3162
FAX: (614) 292-5866
✉huntt.1@osu.edu
Homepage:
http://www.atohio.org

OKLAHOMA

OKLAHOMA ABLE TECH
Oklahoma State University
Wellness Center
1514 W. Hall of Fame Road
Stillwater, OK 74078-2026
Project Manager: Linda Jaco
Phone: (405) 744-9748
Phone: (800) 257-1705 (V/TDD)
FAX: (405) 744-2487
✉mljwell@okstate.edu
Homepage:
http://www.okabletech.okstate.edu

OREGON

OREGON TECHNOLOGY ACCESS FOR LIFE NEEDS PROJECT (TALN)
Access Technologies Inc.
3070 Lancaster Drive NE
Salem, OR 97305-1396
Project Director: Doug Cameron
Phone/TTY: (800) 677-7512
(In-State)
Phone/TTY: (503) 361-1201
FAX: (503) 370-4530
✉dougb41@aol.com
Homepage: http://www.taln.org

PENNSYLVANIA

PENNSYLVANIA'S INITIATIVE ON ASSISTIVE TECHNOLOGY (PIAT)
Institute on Disabilities
Ritter Annex 423
Temple University
Philadelphia, PA 19122
Project Director: Amy Goldman
Phone: (800) 204-7428
TTY: (800) 750-7428
FAX: (215) 204-9371
✉piat@astro.temple.edu
Homepage:
http://www.temple.edu/inst_
disabilities/piat

PUERTO RICO

PUERTO RICO ASSISTIVE TECHNOLOGY PROJECT
University of Puerto Rico, Central Administration, FILIUS Institute
Assistive Technology Institute
Box 365067
San Juan, PR 00936-5067
Project Director: Maria I. Miranda
Phone: (800) 496-6035 (National)
Phone: (800) 981-6033 (In PR)
TTY/FAX: (787) 754-8034
✉pratp@pratp.org
Homepage: http://www.pratp.org

RHODE ISLAND

RHODE ISLAND ASSISTIVE TECHNOLOGY ACCESS PARTNERSHIP (ATAP)
Office of Rehabilitation Services
40 Fountain Street
Providence, RI 02903
Project Director: Regina Connor
Phone: (401) 421-7005 x390
TTY: (401) 421-7016
FAX: (401) 222-3574
✉reginac@ors.state.ri.us
Homepage:
http://www.atap.state.ri.us/

SOUTH CAROLINA

SOUTH CAROLINA ASSISTIVE TECHNOLOGY PROGRAM
USC School of Medicine
University Center for Excellence
Columbia, SC 29208
Project Director: Evelyn Evans
Phone: (803) 935-5263
Phone/TTY: (803) 935-5263
FAX: (803) 935-5342
✉jjendron@usit.net
Homepage:
http://www.public.usit.net/jjendron

SOUTH DAKOTA

SOUTH DAKOTA ASSISTIVE TECHNOLOGY PROJECT
(DAKOTALINK)
1925 Plaza Boulevard
Rapid City, SD 57702
Project Director: Dave Vogel
Phone/TTY: (605) 224-5336
Phone/TTY: (800) 224-5336 (In-State)
FAX: (605) 224-8320
✉dvogel@tie.net
Homepage:
http://dakotalink.tie.net

TENNESSEE

TENNESSEE TECHNOLOGY ACCESS
PROJECT (TTAP)
Citizens Plaza State Office Building, 11th Fl.
400 Deaderick Street
Nashville, TN 37248
Project Director: Kevin Wright
Phone: (615) 532-6553
Phone: (800) 732-5059 (In-State)
Phone/TTY: (615) 741-4566
FAX: (615) 532-4685
✉kwright@mail.state.tn.us
Homepage:
http://www.state.tn.us/mental/ttap.html

TEXAS

TEXAS TECHNOLOGY ACCESS PROJECT
Texas Center for Disability Studies
The University of Texas at Austin
SZB252-D5100
Austin, TX 78712-1290
Information and Referral:
John Moore
Phone: (800) 828-7839
Project Director: Susanne Elrod
Phone: (512) 471-7621
TTY: (512) 471-1844
FAX: (512) 471-7549
✉s.elrod@mail.utexas.edu
Homepage:
http://tcds.edb.utexas.edu

UTAH

UTAH ASSISTIVE TECHNOLOGY PROGRAM
Center for Persons with Disabilities
6588 Old Main Hill
Logan, UT 84322-6588
Program Director:
Judith M. Holt, Ph.D.
Phone: (435) 797-7157
Phone: (435) 797-3824
Phone/TTY: (435) 797-1981
FAX: (435) 797-2355
✉judith@cpd2.usu.edu
Homepage:
http://www.uatpat.org

VERMONT

VERMONT ASSISTIVE TECHNOLOGY PROJECT
103 South Main Street
Weeks Building, First Floor
Waterbury, VT 05671-2305
Project Director: Julie Tucker
Phone/TTY: (800) 750-6355 (In-State)
Phone/TTY: (802) 241-2620
FAX: (802) 241-2174
✉jtucker@dad.state.vt.us
Homepage:
http://www.dad.state.vt.us/atp

VIRGIN ISLANDS

U.S. VIRGIN ISLAND TECHNOLOGY-RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES (TRAID)
University of the Virgin Islands
#2 John Brewers Bay
St. Thomas, VI 00801-0990
Executive Director:
Dr. Yegin Habtes
Phone: (340) 693-1323
FAX: (340) 693-1325
✉yhabtey@ uvi.edu
Homepage:
http://www.uvi.edu/pubrelations/viuapindx.html

VIRGINIA

VIRGINIA ASSISTIVE TECHNOLOGY SYSTEM
8004 Franklin Farms Drive
P.O. Box K-300
Richmond, VA 23288-0300
Information and Referral:
Phone: (800) 435-8490
Project Director: Kenneth Knorr
Phone/TTY: (804) 662-9990
Phone: (800) 552-5019 (In-state)
FAX: (804) 662-9478
✉knorrkh@drs.state.va.us
Homepage: http://www.vats.org

WASHINGTON

WASHINGTON ASSISTIVE TECHNOLOGY ALLIANCE
University of Washington
Center for Technology and Disability Studies
CHDD South Building, Room 104
Box 357920
Seattle, WA 98195-7920
Project Director: Debbie Cook
Phone/TTY: (800) 841-8345 (In-State)
Phone: (800) 214-8731
Phone: (206) 685-4181
TTY: (206) 616-1396
FAX: (206) 543-4779
✉uwat@u.washington.edu
Homepage: http://wata.org

WEST VIRGINIA

WEST VIRGINIA ASSISTIVE TECHNOLOGY SYSTEM (WVATS)
University Center for Excellence in Disabilities
Airport Research and Office Park
955 Hartman Run Road
Morgantown, WV 26505
Project Manager: Jack Stewart
Phone/TTY: (304) 293-4692
Phone: (800) 841-8436 (In-State)
FAX: (304) 293-7294
✉ jstewart@wvu.edu
Homepage:
http://www.ced.wvu.edu/wvats

WISCONSIN

WISTECH
Wisconsin Assistive Technology Program
Division of Supportive Living
P.O. Box 7851
1 W. Wilson Street, Rm. 450
Madison, WI 53707
Project Director: Susan Abbey
Phone: (608) 267-9582
✉abbeysu@dhfs.state.wi.us
FAX: (608) 266-1794
TTY: (608) 267-9880
Homepage:
http://www.wistech.org

WYOMING

WYOMING'S NEW OPTIONS IN TECHNOLOGY (WYNOT) Project
University of Wyoming
1465 North 4th Street, Suite 111
Laramie, WY 82072
Project Director: Kathleen Laurin
Phone/TTY: (307) 766-2084
FAX: (307) 721-2084
✉wynot.uw@uwyo.edu
✉klaurin@uwyo.edu
Homepage: http://wind.uwyo.edu/wynot/wynot.htm

BARRIER FREE LIFTS®

Tonya™
Multi-Purpose Lift With Electric Patient Positoner, Specifically Sized for Children.

Call Us TOLL FREE NATIONWIDE: 800-582-8732

9230 PRINCE WILLIAM ST.
MANASSAS, VA 20110
WEB SITE: http://bfl-inc.com

"Portable" PC-2™

Easily Carried to Other Lifting Areas.

Our Lifts Are:

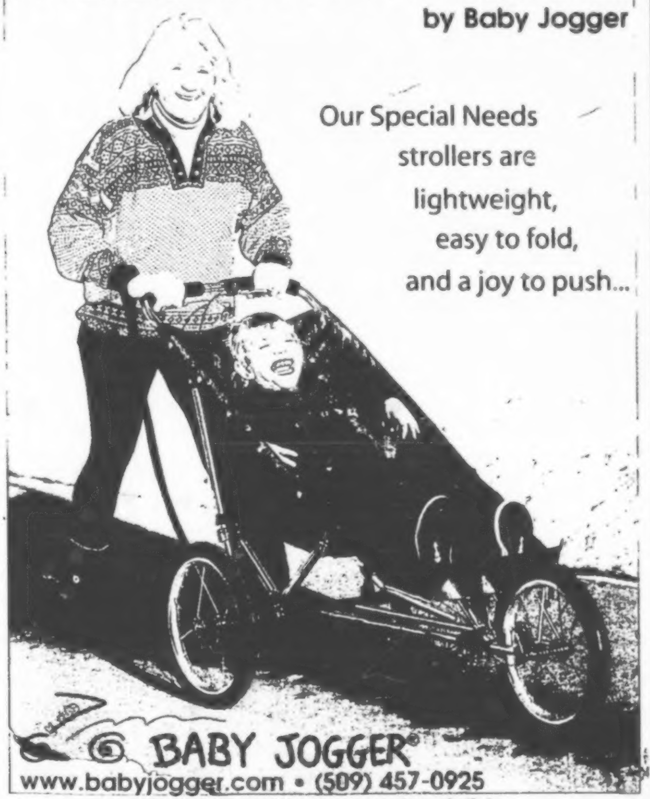
- Premier Ceiling And Floor Model Lifts.
- Ergonomic for Safe Lifting.
- Used Independently or with Assistance.
- Battery Operated.
- Designed to Fit Your Needs! Bathrooms, Bedrooms, Work & School.
- Designed with a Variety of Slings Which Offer a Safe Secure Fit.

"Helping You Achieve Greater Mobility!"

Circle #26 or visit www.eparent.com/adinfo

The BEST strollers in the WORLD!
by Baby Jogger

Our Special Needs strollers are lightweight, easy to fold, and a joy to push...



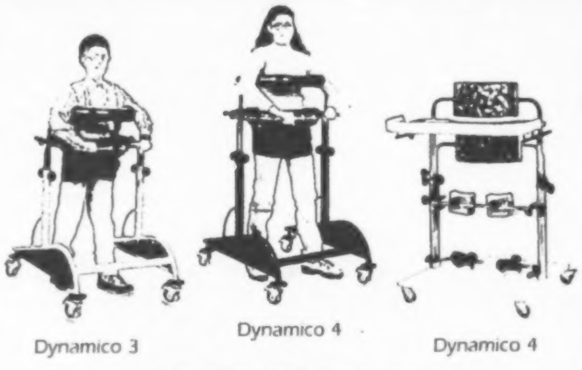
BABY JOGGER®
www.babyjogger.com • (509) 457-0925

Circle #125 or visit www.eparent.com/adinfo

Mr. Mobility
proudly introduces...

ORMESA
WALKERS AND STANDYS

IMPORTED FROM ITALY



Dynamico 3
Dynamico 4
Dynamico 4

For more information call
1-800-555-2909

www.mrmobility.com

Circle #45 or visit www.eparent.com/adinfo

FREEDOM DESIGNS, INC.

Libre Folding Tilt

The new versatile Spectrum Libre Folding Tilt frame has the capability to laterally fold and can tilt up to 45 degrees. Any Freedom Designs, Inc. seating mounting hardware can be adapted to this innovative frame. Highlights include: anodized vibrant colors, variety of footrest options attached to the frame and backpost mounted armrest options. This versatile frame comes in widths of 10 to 18" and seating depths of up to 20" deep. Let the new Spectacular Spectrum Libre give you the freedom you've always wanted in a wheelchair frame!

FREEDOM DESIGNS INCORPORATED

BEST COPY AVAILABLE

FREEDOM DESIGNS INCORPORATED

2241 Madera Road • Simi Valley, CA 93065 USA (805) 582-0077 • (800) 331-8551 • Fax (805) 582-1509

Circle #60 or visit www.eparent.com/adinfo

EasyStand®

range of *motion* made easy . . .

Call for your *free* Standing, Positioning & Mobility Catalog.

800•342•8968 www.easystand.com

Circle #20 or visit www.eparent.com/adinfo

VISION By VIEWPOINT MOBILITY

The **VISION** Advantage:

- Rear entry design doesn't limit you--park and go anywhere
- Not a bulky full-size van-- VISION can fit in a small garage
- Everybody can ride-- seats up to 7 passengers or 2 wheelchairs
- Conversions available on Chrysler and Ford minivans

Let VISION take you on the road to opportunities.

For a **Free Video** or a
personal demonstration of the **VISION** call

Toll Free 1-877-368-6022

Circle #135 or visit www.eparent.com/adinfo

Personalized Interdisciplinary Programs

HMS School for Children with Cerebral Palsy serves children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

Physical & Occupational Therapies
Special Education
Speech/Language Therapy
Music Therapy
Communication Aids
Special Medical Attention
Adapted Recreational Activities

Computer Technology
Communication Devices
Environmental Control
Powered Mobility

HMS, founded in 1882, is open to students two to 21 years. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy
4400 Baltimore Ave, Philadelphia, PA 19104
(215)222-2566

Circle #73 or visit www.eparent.com/adinfo

Care and Guidance for Independence

"Never in my wildest dreams would I have been able to do half of what I've achieved without the help of Crotched Mountain!"

—Brent Reagan '93
Crotched Mountain School

"They treated Steve as if he was their own son...the caring, supportive and experienced staff sets Crotched Mountain apart."

—Cindy and Bill Yuknewicz

"The people at Crotched Mountain helped me believe big things were possible for my daughter."

—Julia Bell

Crotched Mountain School

- Special Education, K-12
- Vocational Services
- Day & Residential Programs

Children's Specialty Hospital

- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@cmf.org

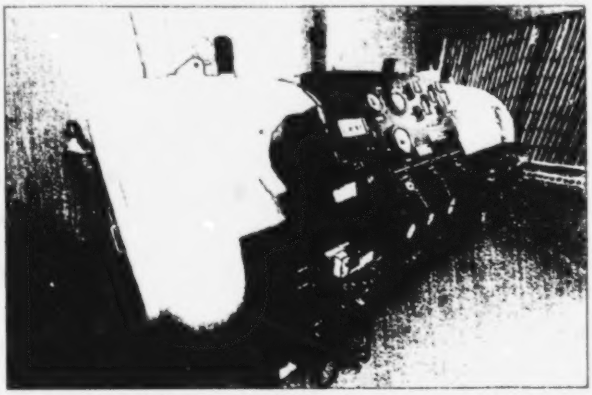
OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

CROTCHED MOUNTAIN

Circle #49 or visit www.eparent.com/adinfo

HYPERBARIC OXYGEN THERAPY

Brain Injuries ~ Cerebral Palsy ~ Near Drowning ~ Stroke ~ MS ~ Lyme Disease



- ✓ Combined 30+ years experience in the hyperbaric field.
- ✓ Care-giver accompanies patient in MULTI-place chambers.
- ✓ NEW chambers with AIR CONDITIONING, entertainment systems and comfortable seating.
- ✓ Experienced Medical Directors are MD's.
- ✓ Facilities are open 7 days/week.
- ✓ Friendly staff makes the experience personal, comfortable, and pleasant.

Two state-of-the-art facilities for your convenience:

Northeast U.S. & Canada

TORONTO HYPERBARIC INC.

Mississauga, Ontario, CANADA
Phone: 905-306-0770
Email: help@torontohyperbaric.com
www.torontohyperbaric.com

Southern U.S.

HyperTec

Olney, Texas, USA
Toll Free: 1-800-218-3588
Email: bbailey@hypertec.ws
www.hyperbaric-health.com

EP neither endorses nor denies the effectiveness of this therapy. For our Editor-in-chief statement see our Contents page.

Circle #131 or visit www.eparent.com/adinfo

FIRSTFlex™

improving reach, grasp and pinch together.

Caring For Life

FIRSTFlex™, for children with spastic hemiplegia, combines patented bracing with electrical stimulation.

Before Treatment

Posture
Grasp

After Treatment

Posture
Grasp

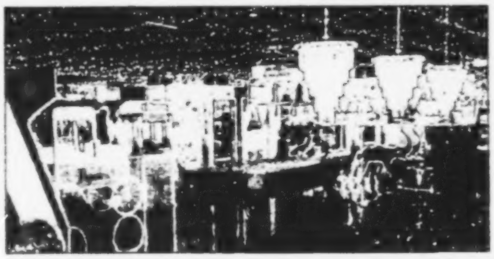
www.ultraflexsystems.com

Call 1-800-220-6670 for free video and research studies.

Circle #132 or visit www.eparent.com/adinfo

JUDGE ROTENBERG CENTER

A Special Education School for Children and Young Adults

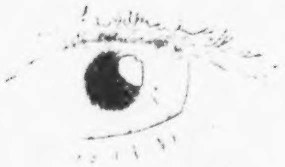


- Serving children and adults with autism, behavior/psychiatric problems and other disabilities
- Highly consistent behavior modification with widest range of treatment procedures available
- Residential and education program
- Minimal use of psychotropic medication
- We accept the most difficult cases
- Employment opportunities available

Please see our web site, www.judgerc.org

240 Turnpike Street, Canton MA 02021
(781) 828-2202 Fax (781) 828-2804 ***www.judgerc.org***

Circle #79 or visit www.eparent.com/adinfo



Discover the faces of Children's Hospital

Everyday we take special care of children. From broken bones to long-term care, from infants to teens. It's our understanding of children and their families that makes us unique.

For over 80 years now, Richmond's Children's Hospital has been providing specialty pediatric care. We understand children. And what it takes to tailor our services to their individual needs.

Take for example, our Pediatric Feeding Disorders Program, one of only a few such services in the country.

Or our Inpatient Rehabilitation Program which helps children who have experienced trauma, disease or impairments return to the activities of daily life.

For adolescents who need subacute care to babies who have never seen the outside world, our Transitional Care Unit is a step toward home. And a place where parents learn to care for their child's special needs.

Discover where children come first.

Children's Hospital
Specialty Services for Children

2924 Brook Road • Richmond, Virginia 23220-1298
(804) 228-5818
www.childrenshosp-richmond.org

We accept most commercial payors, Medicaid HMO's and Medicaid.

Circle #38 or visit www.eparent.com/adinfo

ADAPTIVE RECREATION ORGANIZATIONS

The following national organizations offer adaptive sports and recreational activities and/or information on these topics for people of many abilities. In addition to providing a variety of opportunities for fun and social interaction, some of the listed organizations also offer support groups. Most have local chapters, or they can provide referrals to other local organizations which offer similar activities.

USING THIS DIRECTORY

Numbers correspond to items listed in the **Key to Services.** When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the symbol, ✉. Web sites are listed with the standard **http://** before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

CAMPING/OUTDOOR ACTIVITIES

American Camping Association
5000 State Rd. 67 N.
Martinsville, IN 46151-7902
(800) 428-2267
(765) 342-8456
((765) 349-6357 (fax)
✉bookstore@acacamps.org
http://www.acacamps.org
1,2,4,5,6

Boy Scouts of America
1325 W. Walnut Hill Ln.
Irving, TX 75038
(972) 580-2000
(972) 580-2502 (fax)
http://www.bsa.scouting.org

Breckenridge Outdoor Education Center
PO Box 697
Breckenridge, CO 80424
(800) 383-2632
(970) 453-6422
(970) 453-4676 (fax)
✉boec@boec.org
http://www.boec.org
1,2

Cooperative Wilderness Handicapped Outdoor Group (C.W. HOG)
PO Box 8128
Pocatello, ID 83209
(208) 282-3912
(208) 282-4600 (fax)
✉dayljust@isu.edu
http://www.isu.edu/cwhog/
1,2,4

Girl Scouts of the USA
Membership and Program Group
420 5th Ave.
New York, NY 10018
(800) 223-0624
(212) 852-8000
(212) 852-6515 (fax)
http://www.gsusa.org

SPLORE Accessible Outdoor Adventures
880 East 3375 South
Salt Lake City, UT 84106
(801) 484-4128
(801) 484-4177 (fax)
✉splore@splore.org
http://www.splore.org
1,2,3,4

VISIONS/Vacation Camp for the Blind
500 Greenwich St., 3rd Fl.
New York, NY 10013
(212) 625-1616
(212) 219-4078 (fax)
✉info@visionsvcb.org
http://www.visionsvcb.org
3

Voyageur Outward Bound School
101 E. Chapman St.
Ely, MN 55731
(800) 321-HIKE (4453)
(218) 365-7790
(218) 365-7079 (fax)
✉vobs@vobs.com
http://www.vobs.com

Wilderness Inquiry
808 14th Ave SE
Minneapolis, MN 55414-1516
(800) 728-0719 (voice/TDD)
(612) 676-9400 (voice/TDD)
(612) 676-9401 (fax)
✉info@wildernessinquiry.org
http://www.wildernessinquiry.org
1,3,4,7

Wilderness On Wheels Foundation
3131 S. Vaughn Way, #224
Aurora, CO 80014
(303) 751-3959
✉wow@coloradopros.com
http://www.wildernesonwheels.org
1,2,4,7

CANOEING

American Canoe Association
7432 Alban Station Blvd., Ste B-232
Springfield, VA 22150
(703) 451-0141
(703) 451-2245 (fax)
✉acadirect@aol.com
http://www.aca-paddler.org
1,2,6

FLYING

Freedom's Wings International
1832 Lake Ave.
Scotch Plains, NJ 07076
(908) 232-6354 (phone/fax)
✉raydt@earthlink.net
http://www.freedomswings.org

International Wheelchair Aviators
1117 Rising Hill Way
Escondido, CA 92029
1*; provides information for pilots or future pilots with a disability.*

GOLF

National Amputee Golf Association
Bob Wilson, Exec. Dir.
11 Walnut Hill Rd.
Amhest, NH, 03031
(800) 633-6242
(603) 672-6444(fax)
✉b1naga@aol.com
http://www.nagagolf.org
1,2,4,6,7

US Blind Golf Association
3094 Shamrock St. N.
Tallahassee, FL 32309-2735
(850) 893-4511 (phone/fax)
✉usbga@blindgolf.com
http://www.blindgolf.com

HORSEBACK RIDING

New York Therapeutic Riding Center
336 E. 71st St., 3-D
New York, NY 10021
(212) 535-3917 (phone/fax)
1,2

North American Riding for the Handicapped Association (NARHA)
PO Box 33150
Denver, CO 80233
(800) 369-7433
(303) 452-1212
(303) 252-4610 (fax)
✉narha@narha.org
1,2,4,5,6

ROWING

US Rowing Association
201 S. Capitol Ave., Ste. 400
Indianapolis, IN 46225
(317) 237-5656
(317) 237-5646 (fax)
✉members@usrowing.org
http://www.usrowing.org

SCUBA

Handicapped Scuba Association
1104 El Prado
San Clemente, CA 92672-4637
(949) 498-4540
(949) 498-6128
✉hsa@hsascuba.com
http://www.hascuba.com
1,2,3,4,5

SHOOTING

National Wheelchair Shooting Federation
102 Park Ave.
Rockledge, PA 19046
(215) 379-2359

NRA Disabled Shooting Services
National Rifle Association of America
11250 Waples Mill Rd.
Fairfax, VA 22030
(703) 267-1495
(703) 267-3941 (fax)
http://www.nra.org
2,4,7

SKIING

American Blind Skiing Foundation
610 S. William St.
Mt. Prospect, IL 60056
(847) 255-1739

Ski for Light, Inc.
5 McAuliffe Dr.
North Brunswick, NJ 08902
(609) 520-8079
✉acooke@rfbd.org

National Sports Center for the Disabled
P.O. Box 1290,
Winter Park, CO 80482 USA
(970) 726-1540 or
(303) 316-1540
970.726.4112 (fax)
http://www.nscd.org
(skiing & other sports)

US Disabled Ski Team
PO Box 100
Park City, UT 84060
(435) 649-9090
(435) 649-3613 (fax)
✉info@ussa.org
http://www.usskiteam.org

SOFTBALL

National Wheelchair Softball Association
1616 Todd Ct.
Hastings, MN 55033
(651) 437-1792
(651) 437-3889 (fax)
http://www.wheelchairsoftball.com

TABLE TENNIS

American Wheelchair Table Tennis Association
23 Parker St.
Port Chester, NY 10573
(914) 937-3932 (phone/fax)
1,2

WEIGHTLIFTING

US Wheelchair Weightlifting Association
39 Michael Pl.
Levittown, PA 19057
(215) 945-1964
(215) 946-2574 (fax)
1,3

GENERAL SPORT

AIM for the Handicapped (Adventures in Movement for the Handicapped)
945 Danbury Rd.
Dayton, OH 45420
(800) 332-8210
(937) 294-4611
(937) 294-3783 (fax)
✉aimkids@siscom.net
1,2,4

American Alliance for Health, Physical Education, Recreation, and Dance (AAHPERD)
1900 Association Dr.
Reston, VA 20191-1599
(800) 213-7193
(703) 476-3400
(703) 476-9527 (fax)
✉aalr@aahperd.org
http://www.aahperd.org/aalr.html
1,2,3,6,7,

American Amputee Foundation, Inc.
PO Box 250218
Little Rock, AR 72225
(501) 666-2523
(501) 666-8367 (fax)
1,2,4,7,

American Cancer Society
Home Office
1599 Clifton Rd. NE
Atlanta, GA 30329-4251
(800) 227-2345
http://www.cancer.org

Beneficial Designs, Inc.
1617 Water St. Ste 13
Mindon, NV 89423
(775) 783-8822
✉mail@beneficialdesigns.com
1*; designs adaptive sporting equipment.*

Courage Center
3915 Golden Valley Rd.
Golden Valley, MN 55422
(763) 588-0811
(763) 520-0577 (fax)
✉sports@courage.com
http://www.courage.org

Department of the Interior
Accessibility Management Program
PO Box 37127
Washington, DC 20013
(202) 208-3100
(202) 343-3674 (fax)
✉david_park@nps.gov

Department of Recreation
CB#3185, Evergreen House
730 Airport Rd. UNC
Chapel Hill, NC 27599-3185
(919) 962-0534
(919) 962-1223 (fax)
✉kluken@email.unc.edu
2

Disabled Sports USA
451 Hungerford Dr., Ste. 100
Rockville, MD 20850
(301) 217-0960
(301) 217-0963 (TDD)
(301) 217-0968 (fax)
✉information@dsusa.org
http://www.dsusa.org
1,4,5,6

Houston Challengers
1475 West Gray, Ste. 166
Houston, TX 77018-4926
(713) 521-3737
Wheelchair sports including basketball, bowling, boccia, soccer, and swimming.

National Ability Center (NAC)
PO Box 682799
Park City, UT 84068-2799
(435) 649-3991 (voice/TDD)
(435) 658-3992 (fax)
✉nac@xmission.com
http://www.nationalabilitycenter.org
1

National Center on Accessibility
Indiana Universty
2805 East 10th St. Suite 190
Bloomington, IN 47408-2698
(812) 856-4422 (voice)
(812) 856-4421 (TDD)
✉nca@indiana.edu
http://www.ncaonline.org
1,2,3,4

National Center on Physical Activity and Disability
Universty of Illinios at Chicago
Dept. of Disability and Human Development
College of Applied and Health Sciences
1640 West Roosevelt Rd.
Chicago, IL 60698
(800) 900-8086 (v/TDD)
(312) 355-4058 (Fax)
✉ncpad@uic.edu
http://www.ncpad.org

Paralyzed Veterans of America
801 18th St. NW
Washington, DC 20006
(800) 424-8200
(202) 872-1300
(202) 955-8358
✉bruces@pva.org
http://www.pva.org

Special Olympics International
1325 G St. NW, Ste. 500
Washington, DC 20005
(202) 628-3630
(202) 824-0200 (fax)
✉soimail@aol.com
http://www.specialolympics.org
1,2,5

US Association of Blind Athletes
33 N. Institute St.
Colorado Springs, CO 80903
(719) 630-0422
(719) 630-0616 (fax)
http://www.usaba.org
1,2,4,5

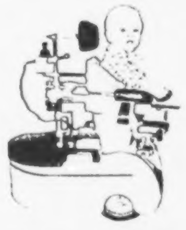
United States Cerebral Palsy Athletic Association
25 W. Independence Way
Kingston, RI 02881
(401) 874-7465
(401) 874-7468 (fax)
✉uscpaa@mail.bbsnet.com
http://www.uscpaa.org
1,2,3,4,5,6,7,8,9

USA Deaf Sports Federation
3607 Washington Blvd., Ste. 4
Ogden, UT 84403-1737
(888) 735-5906 (voice relay)
(801) 393-7916 (TDD)
(801) 393-2263 (fax)
✉homeoffice@usadsf.org
1,2,5

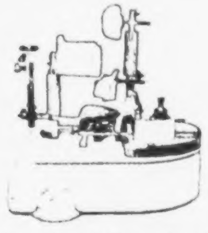
KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts

Early Childhood Mobility
Mini Go-Bot's



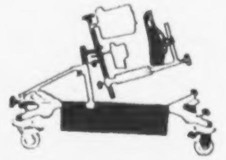
Century Stander



Stanford Standard

Note: Standing frames work with either Go-Bot

Yellow Go-Bot



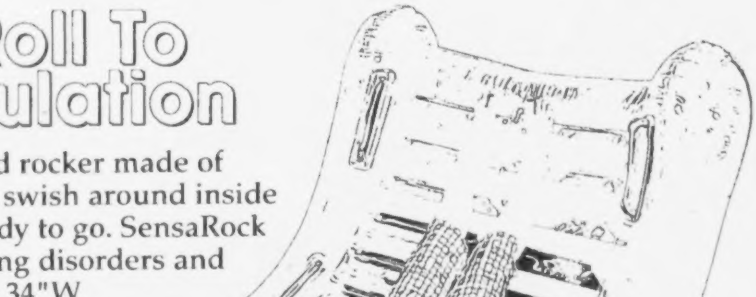
GB-1 Gait Trainer
(can be customized)

Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com

Circle #77 or visit www.eparent.com/adinfo

Rock And Roll To Sensory Stimulation

The SensaRock™ is an inflatable, kid-tested rocker made of high-quality vinyl with 40 small balls that swish around inside when moved. Simply inflate it and it's ready to go. SensaRock is ideal for children with sensory processing disorders and large motor deficiencies. Measures 52"L x 34"W (inner width: 24"). Features 6 handles, 40 balls and numbers and letters that add cognitive appeal. Repair patch included.
The SensaRock, as well as a multitude of other sensory products and information, is available by calling 800-850-8602.



Abilitations™

For more detailed information or to request a free, 240-page catalog filled with products for children's rehabilitation, call 800-850-8602 or visit www.abilitations.com

Circle #120 or visit www.eparent.com/adinfo

CHILDREN'S HOSPITALS

The National Association of Children's Hospitals and Related Institutions (NACHRI) is a national organization of children's hospitals with members in the United States, Canada, Mexico, Puerto Rico, and Singapore. NACHRI promotes the health and well-being of all children and their families through support of children's hospitals and health systems that are committed to excellence in providing healthcare to children. It does so through education, research, health promotion, and advocacy. NACHRI's 160 member institutions work to ensure children's access to healthcare and the continuing ability of children's hospitals to provide services needed by children.

This listing includes NACHRI **members, associates,** and **supporters**. NACHRI members comprise freestanding children's hospitals, children's hospitals within hospitals, and specialty hospitals. The **specialty** children's hospitals provide clinical specialization in • orthopedics, • rehabilitation, • chronic diseases, or • psychiatry. One of the specialty hospitals, Texas Scottish Rite Hospital for Children in Dallas, Texas, is supported by private donations and does not bill for services. The hospital specializes in pediatric orthopedics and learning disabilities and treats children who meet its Texas residency requirements. • A group comprising 22 **Shriners children's hospitals** is also a NACHRI member. These hospitals specialize in orthopedics and burn treatment and provide their very expensive treatments free of charge.

For more information about NACHRI children's hospitals, visit the NACHRI Web site at http://www.childrenshospitals.net. Direct links are available to most members listed under "About NACHRI." For more information about NACHRI contact member services at NACHRI, 401 Wythe Street, Alexandria, VA 22314; telephone: (703) 684-1355; (703) 684-1589 (fax); E-mail: lbaldwin@nachri.org.

MEMBERS-FREESTANDING

ALABAMA

The Children's Hospital of Alabama
Birmingham, AL
(205) 939-9100

ARIZONA

Phoenix Children's Hospital
Phoenix, AZ
(602) 512-8848

ARKANSAS

Arkansas Children's Hospital
Little Rock, AR
(501) 320-1100

CALIFORNIA

Childrens Hospital Los Angeles
Los Angeles, CA
(323) 660-2450

Valley Children's Hospital
Madera, CA
(559) 353-5185

Children's Hospital Oakland
Oakland, CA
(510) 428-3000

Children's Hospital of Orange County
Orange, CA
(714) 997-3000

Lucile Packard Children's Hospital at Stanford
Palo Alto, CA
(650) 497-8000

Children's Hospital and Health Center
San Diego, CA
(858) 576-1700

COLORADO

The Children's Hospital
Denver, CO
(303) 861-8888

CONNECTICUT

Connecticut Children's Medical Center
Hartford, CT
(860) 545-9000

DELAWARE

Alfred I. duPont Hospital for Children
Wilmington, DE
(302) 651-4000

DISTRICT OF COLUMBIA

Children's National Medical Center
Washington, DC
(202) 884-5000

FLORIDA

Miami Children's Hospital
Miami, FL
(305) 666-6511

All Children's Hospital, Inc.
St. Petersburg, FL
(727) 898-7451

GEORGIA

Children's Healthcare of Atlanta
Atlanta, GA
(404) 929-5131

ILLINOIS

The Children's Memorial Hospital
Chicago, IL
(773) 880-4000

LOUISIANA

Children's Hospital
New Orleans, LA
(504) 899-9511

MASSACHUSETTS

Children's Hospital
Boston, MA
(617) 355-6000

MICHIGAN

Children's Hospital of Michigan
Detroit, MI
(313) 745-5437

MINNEAPOLIS

Children's Hospitals and Clinics - Minneapolis
Minneapolis, MN
(612) 813-6100

Children's Hospitals and Clinics - St. Paul
St. Paul, MN
(651) 220-6110

MISSOURI

The Children's Mercy Hospital
Kansas City, MO
(816) 234-3000

Cardinal Glennon Children's Hospital
St. Louis, MO
(314) 577-5600

St. Louis Children's Hospital
St. Louis, MO
(314) 454-6000

NEBRASKA

Children's Hospital
Omaha, NE
(402) 955-5400

OHIO

Children's Hospital Medical Center of Akron
Akron, OH
(330) 543-8200

Children's Hospital Medical Center
Cincinnati, OH
(513) 636-4200

Children's Hospital
Columbus, OH
(614) 722-2000

The Children's Medical Center
Dayton, OH
(937) 641-3000

PENNSYLVANIA

The Children's Hospital of Philadelphia
Philadelphia, PA
(215) 590-1000

Temple University Children's Medical Center
Philadelphia, PA
(215) 707-6100

Children's Hospital of Pittsburgh
Pittsburgh, PA
(412) 692-5325

TENNESSEE

East Tennessee Children's Hospital
Knoxville, TN
(865) 541-8000

Le Bonheur Children's Medical Center, Inc.
Memphis, TN
(901) 572-3000

St. Jude Children's Research Hospital
Memphis, TN
(901) 495-3300

TEXAS

Driscoll Children's Hospital
Corpus Christi, TX
(361) 694-5000

Children's Medical Center of Dallas
Dallas, TX
(214) 456-7000

Cook Children's Medical Center
Fort Worth, TX
(817) 885-4000

Texas Children's Hospital
Houston, TX
(832) 824-1000

Covenant Children's Hospital
Lubbock, TX
(806) 725-0040

UTAH

Primary Children's Medical Center
Salt Lake City, UT
(801) 588-2000

VIRGINIA

Children's Hospital of the King's Daughters Health System
Norfolk, VA
(757) 668-7000

WASHINGTON

Children's Hospital & Regional Medical Center
Seattle, WA
(206) 526-2000

WISCONSIN

Children's Hospital of Wisconsin
Milwaukee, WI
(414) 266-2000

CANADA

Children's & Women's Health Centre of British Columbia
Vancouver, BC
(604) 875-3750

Children's Hospital of Eastern Ontario
Ottawa, ON
(613) 737-2200

The Hospital for Sick Children
Toronto, ON
(416) 813-1500

MEMBERS-SPECIALTY

DISTRICT OF COLUMBIA

The Hospital for Sick Children
Washington, DC
(202) 832-4400

FLORIDA

Shriners Hospitals for Children (Corporate Office)
Tampa, FL
(813) 281-0300

ILLINOIS

La Rabida Children's Hospital and Research Center
Chicago, IL
(773) 363-6700

INDIANA

St. Vincent Children's Specialty Hospital
Indianapolis, IN
(317) 415-5500

MARYLAND

Kennedy Krieger Children's Hospital
Baltimore, MD
(410) 502-9000

Mt. Washington Pediatric Hospital, Inc.
Baltimore, MD
(410) 578-8600

MINNESOTA

Gillette Children's Specialty Healthcare
St. Paul, MN
(651) 229-3838

MONTANA

Shodair Hospital
Helena, MT
(406) 444-7500

NEW JERSEY

Children's Specialized Hospital
Mountainside, NJ
(908) 233-3720

NEW MEXICO

Carrie Tingley Hospital
Albuquerque, NM
(505) 272-5200

NEW YORK

St. Mary's Hospital for Children
Bayside, NY
(718) 281-8800

Blythedale Children's Hospital
Valhalla, NY
(914) 592-7555

OHIO

Cleveland Clinic Children's Hospital for Rehabilitation
Cleveland, OH
(216) 721-5400

PENNSYLVANIA

The Children's Institute
Pittsburgh, PA
(412) 420-2400

TEXAS

Our Children's House at Baylor
Dallas, TX
(214) 820-9838

Texas Scottish Rite Hospital for Children
Dallas, TX
(214) 559-5000

VIRGINIA

Children's Hospital
Richmond, VA
(804) 321-7474

MEMBERS–HOSPITALS WITHIN HOSPITALS

ALABAMA

University of South Alabama Children's and Women's Hospital
Mobile, AL
(334) 415-1000

CALIFORNIA

Loma Linda University Children's Hospital
Loma Linda, CA
(909) 558-8111

Mattel Children's Hospital at UCLA
Los Angeles, CA
(310) 825-5095

University of California Davis Children's Hospital
Sacramento, CA
(916) 734-2000

University of California San Franciso Children's Medical Center
San Francisco, CA
(415) 476-1000

FLORIDA

Shands Children's Hospital at the University of Florida
Gainesville, FL
(352) 265-0111

Wolfson Children's Hospital
Jacksonville, FL
(904) 202-2000

GEORGIA

Hughes Spalding Children's Hospital
Atlanta, GA
(404) 616-6192

Medical College of Georgia Children's Medical Center
Augusta, GA
(706) 721-0211

The Children's Hospital at the Medical Center of Central Georgia
Macon, GA
(478) 633-1104

HAWAII

Kapi'olani Medical Center for Women and Children
Honolulu, HI
(808) 983-6000

IOWA

Blank Children's Hospital
Des Moines, IA
(515) 241-6602

Children's Hospital of Iowa at the University of Iowa Hospitals and Clinics
Iowa City, IA
(319) 384-5437

ILLINOIS

The University of Chicago Children's Hospital
Chicago, IL
(773) 702-6239

Children's Hospital of Illinois at Saint Francis Medical Center
Peoria, IL
(309) 655-3722

INDIANA

James Whitcomb Riley Hospital for Children
Clarian Health
Indianapolis, IN
(317) 274-5000

KENTUCKY

University of Kentucky Children's Hospital
Lexington, KY
(859) 323-6000

Kosair Children's Hospital - Norton Healthcare, Inc.
Louisville, KY
(502) 629-6000

LOUISIANA

Louisiana State University Medical Center-Shreveport
Shreveport, LA
(318) 675-5000

MAINE

The Barbara Bush Children's Hospital at Maine Medical Center
Portland, ME
(207) 871-2353

MARYLAND

Johns Hopkins Children's Center
Baltimore, MD
(410) 955-5000

Maryland's Hospital for Children
Baltimore, MD
(410) 328-6777

MASSACHUSETTS

Floating Hospital for Children at New England Medical Center
Boston, MA
(617) 636-5000

MICHIGAN

C.S. Mott Children's Hospital - University of Michigan Health System
Ann Arbor, MI
(734) 936-4000

MINNESOTA

Mayo Eugenio Litta Children's Hospital - Mayo Clinic
Rochester, MN
(507) 284-2511

MISSOURI

Children's Hospital at University Hospital and Clinics
Columbia, MO
(573) 882-4141

NORTH CAROLINA

Brenner Children's Hospital & Health Services - Wake Forest Univ. Baptist Med. Ctr
Winston-Salem, NC
(336) 716-2011

NORTH DAKOTA

MeritCare Children's Hospital
Fargo, ND
(701) 234-6000

NEW HAMPSHIRE

Children's Hospital at Dartmouth Dartmouth-Hitchcock Medical Center
Lebanon, NH
(603) 650-5000

NEW JERSEY

The Children's Hospital at Hackensack University Medical Center
Hackensack, NJ
(201) 996-2000

Children's Hospital of New Jersey at Newark Beth Israel Medical Center
Newark, NJ
(973) 926-7583

UMDNJ - University Hospital
Newark, NJ
(973) 972-5658

The Bristol Myers Squibb Children's Hospital at Robert Wood Johnson Univ. Hospital
New Brunswick, NJ
(732) 828-3000

St. Joseph's Children's Hospital
Paterson, NJ
(973) 754-2505

NEW YORK

Children's Hospital at Montefiore Medical Center
Bronx, NY
(718) 920-8025

Schneider Children's Hospital - Long Island Jewish Medical Center
New Hyde Park, NY
(718) 470-3000

Children's Hospital of New York New York-Presbyterain
New York, NY
(212) 305-2500

Children's Hospital at Westchester Medical Center
Valhalla, NY
(877) 962-7337

OHIO

Rainbow Babies and Childrens Hospital
Cleveland, OH
(216) 844-3762

Mercy Children's Hospital
Toledo, OH
(419) 251-8000

Tod Children's Hospital
Youngstown, OH
(330) 740-3898

OKLAHOMA

The Children's Hospital at Saint Francis
Tulsa, OK
(918) 494-2200

OREGON

Doernbecher Children's Hospital at the Oregon Health Sciences University
Portland, OR
(503) 418-5195

RHODE ISLAND

Hasbro Children's Hospital at Rhode Island Hospital
Providence, RI
(401) 444-8984

SOUTH CAROLINA

The Children's Hospital
Medical University of South Carolina
Charleston, SC
(843) 792-2123

Children's Hospital of Palmetto Richland
Columbia, SC
(803) 434-4676

TENNESSEE

Children's Hospital at Johnson City Medical Center
Johnson City, TN
(423) 431-6111

Vanderbilt Children's Hospital
Nashville, TN
(615) 322-5000

TEXAS

Children's Hospital of Austin
Austin, TX
(512) 324-8000

Children's Hospital at the University of Texas Medical Branch Hospitals
Galveston, TX
(409) 772-3460

CHRISTUS SANTA ROSA Children's Hospital
San Antonio, TX
(210) 704-2011

VERMONT

Fletcher Allen Health Care
Burlington, VT
(802) 847-2345

VIRGINIA

University of Virginia Children's Medical Center
Charlottesville, VA
(804) 924-9821

Inova Fairfax Hospital for Children
Falls Church, VA
(703) 204-6008

WEST VIRGINIA

Charleston Area Medical Center - Women and Children's Hospital
Charleston, WV
(304) 348-2752

WISCONSIN

University of Wisconsin Children's Hospital
Madison, WI
(608) 263-6400

ASSOCIATES

ALASKA

The Children's Hospital at Providence Alaska Medical Center
Anchorage, AK
(907) 261-2211

ARIZONA

Children's Health Center - St. Joseph's Hospital
Phoenix, AZ
(602) 406-3000

FLORIDA

Joe DiMaggio Children's Hospital at Memorial Regional Hospital
Hollywood, FL
(954) 987-2000

Arnold Palmer Hospital for Children & Women - Orlando Regional Healthcare System
Orlando, FL
(407) 649-6960

Tampa General Healthcare Children's Medical Center
Tampa, FL
(813) 251-7000

MASSACHUSETTS

Baystate Medical Center Children's Hospital
Springfield, MA
(413) 794-5060

MICHIGAN

Hurley Medical Center, Tuuri Children's Center
Flint, MI
(810) 257-9000

De Vos Children's Hospital
Grand Rapids, MI
(616) 391-1898

Bronson Methodist Hospital
Kalamazoo, MI
(616) 341-8820

Sparrow Regional Children's Center - Sparrow Hospital & Health System
Lansing, MI
(517) 483-2700

CHILDREN'S HOSPITALS

NORTH CAROLINA

North Carolina Children's Hospital - University of North Carolina Hospitals
Chapel Hill, NC
(919) 966-4131

Carolinas Medical Center
Charlotte, NC
(704) 355-2000

Children's Hospital - University Health Systems of Eastern North Carolina
Greenville, NC
(252) 816-4100

OHIO

Cleveland Clinic Children's Hospital
Cleveland, OH
(216) 444-2200

Toledo Children's Hospital
Toledo, OH
(419) 291-4100

PENNSYLVANIA

PennState Children's Hospital at The Milton S. Hershey Medical Center
Hershey, PA
(717) 531-6700

SOUTH CAROLINA

Children's Hospital of the Greenville Hospital System
Greenville, SC
(864) 558-8860

TEXAS

Memorial Hermann Children's Hospital
Houston, TX
(713) 704-4000

SINGAPORE

KK Women's and Children's Hospital
Singapore
011-65-293-4044

SUPPORTERS

ALABAMA

Huntsville Hospital, Pediatric Department
Huntsville, AL
(256) 517-7981

FLORIDA

Chris Evert Women and Children's Center, Broward General Medical Center
Fort Lauderdale, FL
(954) 355-5800

The Children's Hospital of Southwest Florida - Lee Memorial Health System
Fort Myers, FL
(941) 332-1111

Nemours Children's Clinic - Jacksonville
Jacksonville, FL
(904) 390-3600

Baptist Children's Hospital
Miami, FL
(305) 596-6503

Tampa Children's Hospital at St. Joseph's
Tampa, FL
(813) 870-4662

GEORGIA

George and Marie Backus Children's Hospital at Memorial Health Univ. Med. Ctr.
Savannah, GA
(912) 350-8000

IDAHO

St. Luke's Children's Hospital
St. Luke's Regional Medical Center
Boise, ID
(208) 381-2116

LOUISIANA

Our Lady of the Lake Regional Medical Center
Baton Rouge, LA
(225) 765-6565

MICHIGAN

Detroit Institute for Children
Detroit, MI
(313) 832-1100

MINNESOTA

Hennepin County Medical Center
Minneapolis, MN
(612) 347-2121

NORTH CAROLINA

Ruth & Billy Graham Children's Health Ctr. at Mission St. Joseph's
Asheville, NC
(828) 213-1741

NEVADA

Sunrise Children's Hospital
Las Vegas, NV
(702) 731-8000

NEW JERSEY

Voorhees Pediatric Facility
Voorhees, NJ
(856) 346-3300

OKLAHOMA

Children's Hospital of Oklahoma University Health Partners
Oklahoma City, OK
(405) 271-5911

PENNSYLVANIA

St. Christopher's Hospital for Children
Philadelphia, PA
(215) 427-5000

TEXAS

North Texas Hospital for Children at Medical City Dallas
Dallas, TX
(972) 566-8888

WASHINGTON

MultiCare Health System - Mary Bridge Children's Hospital and Health Center
Tacoma, WA
(253) 403-1400

PUERTO RICO

San Jorge Children's Hospital
Santurce, PR
(787) 727-1000

CANADA

Children's Hospital at Hamilton Health Sciences Corporation
Hamilton, ON
(905) 521-2100

SHRINERS

CALIFORNIA

Shriners Hospitals for Children - Los Angeles
Los Angeles, CA
(213) 388-3151

Shriners Hospitals for Children - Sacramento
Sacramento, CA
(916) 453-2000

FLORIDA

Shriners Hospitals for Children - Tampa
Tampa, FL
(813) 972-2250

HAWAII

Shriners Hospitals for Children - Honolulu
Honolulu, HI
(808) 941-4466

ILLINOIS

Shriners Hospitals for Children - Chicago
Chicago, IL
(773) 622-5400

KENTUCKY

Shriners Hospitals for Children - Lexington
Lexington, KY
(859) 266-2101

LOUISIANA

Shriners Hospitals for Children - Shreveport
Shreveport, LA
(318) 222-5704

MASSACHUSETTS

Shriners Hospitals for Children - Boston
Boston, MA
(617) 722-3000

Shriners Hospitals for Children - Springfield
Springfield, MA
(413) 787-2000

MINNESOTA

Shriners Hospitals for Children - Twin Cities
Minneapolis, MN
(612) 596-6100

MISSOURI

Shriners Hospitals for Children - St. Louis
Saint Louis, MO
(314) 432-3600

OHIO

Shriners Hospitals for Children - Cincinati
Cincinnati, OH
(513) 872-6000

OREGON

Shriners Hospitals for Children - Portland
Portland, OR
(503) 241-5090

PENNSYLVANIA

Shriners Hospitals for Children - Erie
Erie, PA
(814) 875-8700

Shriners Hospitals for Children - Philadelphia
Philadelphia, PA
(215) 430-4000

SOUTH CAROLINA

Shriners Hospitals for Children - Greenville
Greenville, SC
(864) 271-3444

TEXAS

Shriners Hospitals for Children - Galveston
Galveston, TX
(409) 770-6600

Shriners Hospitals for Children - Houston
Houston, TX
(713) 797-1616

UTAH

Shriners Hospitals for Children - Intermountain
Salt Lake City, UT
(801) 536-3500

WASHINGTON

Shriners Hospitals for Children - Spokane
Spokane, WA
(509) 455-7844

CANADA

Shriners Hospitals for Children - Montreal
Montreal, PQ
(514) 842-4464

MEXICO

Shriners Hospitals for Children - Mexico
Mexico, DF
011-(525) 618-1120

TITLE V

Every state has a Title V Program which is funded, in part, through the Federal Title V Block Grant that provides health-related services to children with special healthcare needs—sometimes abbreviated as "CSHCN"—and their families. Title V Programs also provide assistance in accessing other services that CSHCN and their families need, such as parent support and information networks. The financial eligibility criteria, residency criteria, and medical eligibility criteria for these Programs varies from state to state. These Programs are also known by different names in different states. The following is a list of contacts in each of the state Title V CSHCN Programs. The listing is based on the "Directory of State Title V CSHCN Programs: Eligibility and Scope of Services." This report was developed by the Institute for Child Health Policy in Gainesville, FL, with financial support from the Maternal and Child Health Bureau, (US Department of Health and Human Services) and with technical assistance from the Association of Maternal and Child Health Programs. The information contained in this report is also available through the Internet. The address on the World Wide Web is http://www.ichp.edu.

USING THIS DIRECTORY

When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard http:// before each. E-mail addresses are indicated by the symbol, ⊠. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

Children's Rehabilitation Services
Department of Education
Contact Person: Christine Kendall
(334) 281-8780 ext.281
(334) 281-1973 (fax)
⊠ckendall@rehab.state.al.us
2129 East South Blvd.
PO Box 11586
Montgomery, AL 36111-0586

ALASKA

Section of Maternal, Child, and Family Health
Contact Person:
Karen Martinek Director
(907) 269-3423
(907) 269-3465 (fax)
⊠karen_martinek@health.state.ak.us
Department of Health
and Social Services
3601 C Street Ste. 934
PO Box 240249
Anchorage, AK 99524-0249

ARIZONA

Office of Children with Special Health Care Needs (CSHCN)
Contact Person:
Susan Burke Chief
(602) 542-1860
(602) 542-2589 (fax)
⊠sburke@hs.state.az.us
Department of Health Services
2927 North 35th Ave Ste 200
Phoenix, AZ 85017

ARKANSAS

Children's Medical Services
Department of Human Services
Contact Person: Nancy Church
Program Director
(501) 682-1464
(501) 682-8247 (fax)
⊠nancy.church@medicaid.state.ar.us
PO Box 1437 Slot 5380
Little Rock, AR 72203-1437

CALIFORNIA

Children's Medical Services Branch
California Department of Health
Services (DHS)
Contact Person: Maridee A.
Gregory, MD Chief
(916) 327-2487
(916) 327-1106 (fax)
⊠gregory@dhs.ca.gov
1515 K Street, Ste. 400
PO Box 942732
Sacramento, CA 95814

COLORADO

Health Care Program for Children with Special Needs (HCD)
Contact Person:
Kathy Watters Director
(303) 692-2418
(303) 782-5576 (fax)
⊠kwatters@state.co.us
Colorado Department Of Public
Health and Environment
4300 Cherry Creek Dr. S.
Denver, CO 80246-1530

CONNECTICUT

Family Health Services Division-BCH
Connecticut Department of Public
Health
Contact Person:
Beth Weinstein Director
MCH
Ann Marie Montemerlo
CSHCN Supervisor
(860) 509-8066
(860) 509-7720 (fax)
⊠beth.weinstein@po.state.ct.us
⊠annmarie.montemerlo@po.state.ct.us
410 Capitol Ave. M/S/11-FHS
PO Box 340308
Hartford, CT 06134-0308

DELAWARE

Children with Special Health Care Needs
Division of Public Health
Contact Person: Dennis Rubino
Director
(302) 739-4785
(302) 739-5617 (fax)
⊠drubino@state.de.us
Federal & Water Sts
PO Box 637
Dover, DE 19903

DISTRICT OF COLUMBIA

Acting Chief, CSHCN Unit
DC Department of Health, Office
of Maternal and Child Health
Contact Person: Joyce Brooks
Acting Chief
(202) 442-9338
(202) 442-4950 (fax)
⊠joyce.brooks@dc.gov
825 N. Capitol Street NE
Washington, DC 20002

FLORIDA

Deputy Secretary/Deputy State Health Officer
Department of Health
Children's Medical Services
Contact Person: John Agwunobi
Deputy Secretary/Deputy State
Health Officer
(850) 245-4210
(850) 410-0501 (fax)
⊠john_agwunobi@doh.state.fl.us
4052 Bald Cypress Way, Bin A-06
Tallahassee, FL 32399-1707

GEORGIA

CMS, Title V CSHCN
Contact Person: Wendy Sanders
Director
(404) 657-2724
(404) 657-2763 (fax)
⊠wsanders@dhr.state.ga.us
2 Peachtree Street, Room 11-205
Atlanta, GA 30303-3186

HAWAII

Children with Special Health Care Needs Branch (CSHCN)
Contact Person:
Patricia Heu, MD Chief
(808) 733-9070
(808) 733-9068 (fax)
⊠plheu@mail.fhsd.health.state.hi.us
Hawaii State
Department of Health\
741 Sunset Ave.
Honolulu, HI 96816

IDAHO

Children's Special Health Program (CSHP) Bureau Of Clinical and Preventive Services
Contact Person: Brett S. Harrell
(208) 334-5962
(208) 332-7307 (fax)
⊠harrell@idhw.state.id.us
Idaho Department
of Health and Welfare
450 W. State St. 4th Fl.
PO Box 83720
Boise, ID 83720-0036

ILLINOIS

Division of Specialized Care for Children
University of Illinois at Chicago
Contact Person: Charles N.
Onufer, MD Director
(217) 793-2340
(217) 793-0773 (fax)
⊠conufer@uic.edu
2815 W. Washington Ste. 300
PO Box 19481
Springfield, IL 62794-9481

INDIANA

Children's Special Health Care Services
Contact Person: Wendy
Gettelfinger, RN JD Interim
Title V Director
(317) 233-5578
(317) 233-6609 (fax)
⊠wgettelf@isdh.state.in.us
Indiana State Department
of Health
2 N. Meridian St. Section 7-B
Indianapolis, IN 46204

IOWA

Child Health Specialty Clinics
Contact Person:
Dr Jeffrey Lobas Title V Director
(319) 356-4107
(319) 356-3715 (fax)
⊠jeffrey_lobas@uiowa.edu
University Hospital School
100 Hawkins Drive, Rm. 247
Iowa City, IA 52242-1011

KANSAS

Services for Children with Special Health Care Needs
Contact Person: Jamey Kendall,
RN, BSN Director
(785) 296-1316
(785) 296-8616 (fax)
⊠jkendall@kdhe.state.ks.us
Kansas Department of Health and
Environment
1000 SW Jackson Ste. 220 Rm.
1005N LSOB
Topeka, KS 66612-1274

KENTUCKY

Commission for Children with Special Health Care Needs (CCSHCN)
Contact Person:
Eric Friedlander Director
(502) 595-4459 X 271
(502) 595-4673 (fax)
⊠eric.friedlander@mail.state.ky.us
Commission for Children with
Special Health Care Needs
982 Eastern Parkway
Louisville, KY 40217

LOUSIANA

Office of Public Health
Contact Person: Linda Rose
Program Administrator
(504) 568-5055
(504) 568-7529 (fax)
⊠lrose@dhh.state.la.us
Office of Public Health
325 Loyola Ave. Rm. 607
PO Box 60630
New Orleans, LA 70112

MAINE

Coordinated Care Services CSHCN
Contact Person: Toni Wall Director
(207) 287-5139
(207) 287-5355 (fax)
⊠toni.g.wall@state.me.us
Department of Human Services
Key Plaza 7th Floor
Augusta, ME 04333

MARYLAND

Division of Specialty Care and Regional Resource Development
Contact Person: Susan Panny,
Chief
(410) 333-5047
(410) 767-6730 (fax)
⊠pannys@dhmh.state.md.us
Office of Genetics and Children's
Special Health Needs
201 W. Preston Street Rm. 321-A
Baltimore, MD 21201

MASSACHUSETTS

Massachusetts Department of Public Health
250 Washington St. 5th Fl.
Boston, MA 02108-4619

Bureau of Family and Community Health
Contact Person: Deborah Klein
Walker, EdD Associate
Commissioner
(617) 624-5222
(617) 624-5261 (fax)
⊠debbie.walker@state.ma.us

Division for Children with Special Health Care Needs (CSHCN)
Bureau of Family and Community
Health
Massachusetts Department of
Public Health
Contact Person: Deborah Allen
Director
(617) 624-5070
(617) 624-5990 (fax)
⊠debby.allen@state.ma.us
250 Washington St. 4th Fl.
Boston, MA 02108-4619

MICHIGAN

Children with Special Health Needs
Contact Person: Jane Finn, Chief
(517) 241-7186
(517) 241-8970 (fax)
⊠finnj@state.mi.us
Michigan Department of
Community Health
PO Box 30479
Lansing, MI 48909

TITLE V

MINNESOTA
MCSHN
Contact Person: John Hurley
Title V Acting CSHCN Chief
(651) 281-9884
(651) 215-8953 (fax)
✉john.hurley@health.state.mn.us
MCSHN
Division of Family Health
85 East 7th Place
PO Box 9441
St. Paul, MN 55164-0882

MISSISSIPPI
Children's Medical Program
Contact Person: Mike Gallarno
(601) 987-3965
(601) 987-5560 (fax)
✉mgallarno@msdh.state.ms.us
Department of Health
421 Stadium Circle Drive
PO Box 1700
Jackson, MS 39215-1700

MISSOURI
Division of Material, Child and Family Health
Contact Person:
Rick Horrell Director
(573) 751-6461
(573) 751-6237 (fax)
✉horrer@dhss.state.mo.us
Division of Material, Child and
Family Health
930 Wildwood St
PO Box 570
Jefferson City, MO 65102

MONTANA
Special Health Services
Contact Person:
Sharon S. Wagner Section Supervisor
(406) 444-3622
(406) 444-2750 (fax)
✉shwagner@state.mt.us
Department of Public Health and
Human Services
1400 Broadway Rm. C-314
Cogswell Bldg.
PO Box 202951
Helena, MT 59620

NEBRASKA
Division of Aging and Disability Services
Contact Person: Mary Jo Iwan
Administrator
(402) 471-9345
(402) 471-6352 (fax)
✉maryjo.iwan@hhss.state.ne.us
Nebraska Department of Health
and Human Services
301 Centennial Mall S. 5th Fl.
PO Box 95044
Lincoln, NE 68509-5044

NEVADA
Bureau of Family Health Services
Contact Person:
Judith Wright Bureau Chief
(775) 684-4285
(775) 684-4245 (fax)
✉jwright@govmail.state.nv.us
Nevada State Health Division
505 E. King St. Rm. 200
Carson City, NV 89701-4792

NEW HAMPSHIRE
Special Medical Services
Contact Person:
Jane Hybsch Title V Director,
(603) 271-4488
(603) 271-4902 (fax)
✉Jhybsch@dhhs.state.nh.us
NH Department of Health and
Human Services
Community and Public Health
6 Hazen Drive
Concord, NH 03301-6527

NEW JERSEY
Special Child and Adult Health Services
Contact Person:
Gloria Jones-Grant Director
(609) 984-0755
(609) 292-3580 (fax)
✉gloria.jones-grant@doh.state.nj.us
New Jersey Department of Health
and Senior Services
50 E. State St.
PO Box 364
Trenton, NJ 08625-0364

NEW MEXICO
Children's Medical Services
Contact Person: Marilyn Sakara
MCH Director
Lynn Christiansen
CSHCN Director
(505) 476-8868
(505) 476-8896 (fax)
✉marilyns@doh.state.nm.us
✉lchristiansen@doh.state.nm.us
Department of Health and
Environment
2040 South Pacheco
PO Box 26110
Santa Fe, NM 87505

NEW YORK
Bureau of Child and Adolescent Health
Contact Person: Nancy Kehoe
Director
(518) 474-2001
(518) 473-8673 (fax)
✉nak01@health.state.ny.us
New York State
Department of Health
Empire State Plaza Rm. 208
Corning Tower
Albany, NY 12237-0618

NORTH CAROLINA
Division of Public Health, Women's and Children's Health Section
Contact Person: Carol Tant, Head,
Children and Youth Branch
(919) 715-3193
(919) 715-3187 (fax)
✉carol.tant@ncmail.net
Department of Health and
Human Services, Division of Public
Health, Women's and Children's
Health Section
1928 Mail Service Center
Raleigh, NC 27699-1928

NORTH DAKOTA
Children's Special Health Services
Contact Person: Tamara Gallup-Millner, Director
(701) 328-2436
(701) 328-2359 (fax)
✉sogalt@state.nd.us
North Dakota Department of
Human Services
600 E. Boulevard Ave
State Capitol Bldg. Dept. 325
Bismarck, ND 58505-0269

OHIO
Bureau for Children with Medical Handicaps
Contact Person: James Bryant,
MD Chief
(614) 466-1547
(614) 728-3616 (fax)
✉jbryant@gw.odh.state.oh.us
Ohio Department of Health
246 N. High St.
PO Box 1603
Columbus, OH 43266-1603

OKLAHOMA
CSHCN
Contact Person: Frank Gault
(405) 521-4394
(405) 521-4158 (fax)
✉frank.gault@okdhs.org
Department of Human Services
PO Box 25352
Oklahoma City, OK 73125

OREGON
Child Development and Rehabilitation Center
Director, Contact Person:
Clifford J (Jerry) Sells, MD MPH
(503) 494-8362
(503) 494-6868 (fax)
✉sellsc@ohsu.edu
Oregon Health Sciences University
PO Box 574
Portland, OR 97207-0575

PENNSYLVANIA
Division of Child and Adult Health Services
Contact Person: C Gail Stock
(717) 783-5436
(717) 772-0323 (fax)
✉cstock@state.pa.us
Department of Health
Commonwealth & Forester
7th Floor East Wing
PO Box 90
Harrisburg, PA 17108

RHODE ISLAND
Division of Family Health
Contact Person: C Gail Stock
(401) 222-5928
(401) 222-1442 (fax)
✉peters@doh.state.ri.us
Rhode Island
Department of Health
3 Capitol Hill Rm. 302
Providence, RI 02908-5097

SOUTH CAROLINA
Division of Children's Rehabilitative Services
Contact Person: Linda D. Price
Deputy Medical Director
(803) 898-0784
(803) 898-0613 (fax)
✉priceld@columbia63.dhec.state.sc.us
Department of Health &
Environmental Control
Mills/Jarrett Complex
PO Box 101106
Columbia, SC 29201

SOUTH DAKOTA
MCH Coordinator/ Program Manager CSHS
Maternal and Child Health
Contact Person:
Nancy Hoyme, Director
(605) 773-3737
(605) 773-5942 (fax)
✉nancyhoyme@doh.state.sd.us
Division of Health Services
South Dakota
Department of Health
615 East 4th St.
Pierre, SD 57501

TENNESSEE
Children's Special Services Program
Tennessee Department of Health
Contact Person:
Mary Jane Dewey MCH
Coordinator/Program
Manager CSHS
(615) 741-0310 or
(615) 741-8530
(615) 741-1063 (fax)
✉mdewey@mail.state.tn.us
Maternal and Child Health,
Children's Special Services
425 5th Ave. N., 5th Fl.
Cordell Hull Bldg.
Nashville, TN 37247-4701

TEXAS
CSHCN Planning and Policy Development Division
Contact Person: Susan C.
Penfield, MD Director
(512) 458-7355
(512) 458-7238 (fax)
✉susan.penfield@tdh.state.tx.us
Texas Department of Health
Bureau of Children's Health
1100 W. 49th St.
Austin, TX 78756-3179

UTAH
Community and Family Health Service Division
Contact Person: Vera Francis Tait
MD Bureau Director CSHCN
(801) 584-8239
(801) 538-6510 (fax)
✉ftait@doh.state.ut.us
Utah Department of Health-
Directors Office
144610 North Medical Drive
Salt Lake City, UT 84114-4616

VERMONT
Children with Special Health Needs (CSHN), Agency of Human Services
Contact Person: Carol R. Hassler,
MD Director
(802) 863-7338
(802) 863-7635 (fax)
✉chassle@vdh.state.vt.us
Vermont Department of Health
108 Cherry St.
PO Box 70
Burlington, VT 05402

VIRGINIA
Children with Special Health Care Needs (CSHCN)
Contact Person: Nancy Bullock,
RN MPH
(804) 786-3693
(804) 225-3307 (fax)
✉nbullock@vdh.state.va.us
Virginia Department of Health
1500 E. Main Street Room 138
PO Box 2448
Richmond, VA 23218

WASHINGTON
Department of Health Maternal and Child Health
Contact Person: Jan Fleming
Acting Director
(360) 236-3521
(360) 236-2323 (fax)
✉jan.fleming@doh.wa.gov
Department of Health
Maternal and Child Health
PO Box 47880
7211 Cleanwater Lane,
Building #10
Olympia, WA 98504-7835

WEST VIRGINIA
Division of Children's Specialty Care
Contact Person: Janet Lucas
(304) 558-5388
(304) 558-2866 (fax)
✉janetlucas@wvdhhr.org
Office of Maternal & Child Health
350 Capital Street Rm. 427
Charleston, WV 25301-3714

WISCONSIN
Children with Special Health Needs
Contact Person:
Peggy Helm-Quest
CSHCN Unit Supervisor
(608) 267-2945
(608) 267-3824 (fax)
✉helmqp@ddhfs.state.wi.us
Bureau for Family and
Community Health
Division of Public Health
1 West Wilson Street Room 351
Madison, WI 53702

WYOMING
Children's Special Health Services
Contact Person: Dorothy Ailes
Program Manager
(307) 777-5413
(307) 777-7215 (fax)
✉dailes@state.wy.us
Community and Family Health
Hathaway Bldg. Rm. 467
Cheyenne, WY 82002

ADA PROJECTS

Disability and Business Technical and Assistance Centers

The National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education has established ten regional Disability and Business Technical Assistance Centers (DBTACs) to provide information, training, and technical assistance to employers, people with disabilities, advocates for people with disabilities and other entities with responsibilities under the Americans with Disabilities Act (ADA).

The centers act as a "one-stop" central, comprehensive resource on ADA issues in employment, public services, public accommodations (private for profit and non-profit businesses), and communications. Each center works closely with local business, disability, governmental, rehabilitation, and other professional networks to provide ADA information and assistance. Programs vary in each region, but all centers provide the following:

- Technical Assistance
- Education and Training
- Materials Dissemination
- Information and Referral
- Public Awareness
- Local Capacity Building

The DBTACs are also providing information and technical assistance on education-based information technology, such as websites, software and hardware, in collaboration with the National Center on Accessible Information Technology in Education (AccessIT). Contact:

AccessIT
Box 355670
University of Washington
Seattle, WA 98195-5670
206-616-2223 (voice and TDD)
1-866-968-2223 (Toll Free V/TDD)
206-221-4171 (FAX)
✉accessit@u.washington.edu
http://www.washington.edu/accessit/

Using this directory

Contact the DBTAC's toll-free at: (800) 949-4232 (voice/TDD). Your call will automatically be routed to the DBTAC in your region.

This list was provided by Adaptive Environments, the New England DBTAC. When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard http:// before each. E-mail addresses are indicated by the symbol ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

National Access for Public Schools Project

The National Access for Public Schools Project has also been funded by NIDRR to answer questions about the ADA in public schools. For information, contact Adaptive Environments, Inc., at 374 Congress St., Ste. 301 Boston, MA 02210; (800) 893-1225, Ext.28 (voice/TDD). They can also be found on the Internet at http://www.adaptenv.org.

REGION 1 (CT, MA, ME, NH, RI, VT)

New England DBTAC
Adaptive Environments Center, Inc.
374 Congress St., Ste. 301
Boston, MA 02210
(617) 695-0085 (V/TDD)
(617) 482-8099 (fax)
✉adaptive@adaptenv.org
http://www.adaptenv.org

REGION 2 (NJ, NY, PR, VI)

Northeast DBTAC
Cornell University
107 ILR Extension Building
Ithaca, NY 14853
(607)-255-8348 voice
(607)-255-2891 (TDD)
(607) 255-2763 (fax)
✉ah45@cornell.edu.
http://www.nedbtac.org

REGION 3 (DC, DE, MD, PA, VA, WV)

Mid-Atlantic DBTAC
TransCen, Inc.
451 Hungerford Dr., Ste. 607
Rockville, MD 20850
(301) 217-0124 (V/TDD)
(301) 217-0754 (fax)
✉adainfo@transcen.org
http://www.adainfo.org

REGION 4 (AL, FL, GA, KY, MS, NC, SC, TN)

Southeast DBTAC
UCP National Center for
Rehabilitation Technology
at Georgia Tech
490 Tenth St.
Atlanta, GA 30318
(404) 385-0636 (V/TDD)
(404) 385-0641 (fax)
✉se-dbtac@mindspring.com
http://www.sedbtac.org

REGION 5 (IL, IN, MI, MN, OH, WI)

Great Lakes DBTAC
University of Illinois/Chicago
Department on Disability &
Human Development
1640 West Roosevelt Rd.
Chicago, IL 60608
(312) 413-1407 (V/TDD)
(312) 413-1856 (fax)
✉gldbtac@uic.edu
http://www.adagreatlakes.org

REGION 6 (AR, LA, NM, OK, TX)

Southwest DBTAC
Independent Living Research
Utilization
2323 South Shepherd Blvd., Ste. 1000
Houston, TX 77019
(713) 520-0232 (V/TDD)
(713) 520-5785 (fax)
✉swdbtac@ilrv.org
http://www.ilru.org

REGION 7 (IA, KS, MO, NE)

Great Plains DBTAC
ADA Project
100 Corporate Lake Dr.
Columbia, MO 65203
(573) 882-3600 (V/TDD)
(573) 884-4925 (fax)
✉adalh@showme.missouri.edu
http://www.adaproject.org

REGION 8 (CO, MT, ND, SD, UT, WY)

Rocky Mountain DBTAC
Meeting the Challenge, Inc.
3630 Sinton Rd., Ste. 103
Colorado Springs, CO 80907
(719) 444-0268 (V/TDD)
(719) 444-0269 (fax)
✉regionVIII@mtc.inc.com
http://www.ada-infonet.org.

REGION 9 (AZ, CA, HI, NV, PACIFIC BASIN)

Pacific DBTAC
California Public Health Institute
2168 Shattuck Ave., Ste. 301
Berkeley, CA 94704-1307
(510) 848-2980
(510) 848-1840 (TDD)
(510) 848-1981 (fax)
✉adatech@pdbtac.com
http://www.pacdbtac.org

REGION 10 (AK, ID, OR, WA)

Northwest DBTAC
Northwest ADA/IT Center
P.O. Box 574
Portland, Oregon 97207-0574
(503) 494-4001 (V/TDD)
(503) 494-6868
✉nwada@ohsu.edu
http://www.nwada.org

With the Creepster Crawler, You Can Watch Your Child Crawl for the First Time!

Children lacking head control, the ability to roll over or belly crawl have gained mobility with the ***Creepster Crawler.*** Using this light, innovative device, hundreds of children around the world are crawling, working more productively with their therapists, and gaining a head start to more advanced mobility in the future.

The ***Creepster Crawler*** is an ideal solution for youngsters with debilitating conditions such as ☐ Spina Bifida ☐ Down Syndrome ☐ Cerebral Palsy ☐ TBI, and ☐ developmental delays. Children with tracheostomies and G-Tubes also are successful users of the ***Creepster Crawler***.

The ***Creepster Crawler***'s frame has a padded platform that can support a parent or therapist from above, making it easier to work with the child on weight-bearing, weight-shifting, reaching and creeping. Front shoulder, chest and rear straps can be adjusted for individual fit.

Please visit our Worldwide Web site at www.red-enter.com for additional details and a video demonstration of the ***Creepster Crawler***.

Call for a Brochure!

1-800-577-1317

Fax: 1-602-242-9211

or email us at info@red-enter.com

RedBarn ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at

www.red-enter.com

CAUTION: Children should not be left unattended in the Creepster Crawler.

Circle #111 or visit www.eparent.com/adinfo

TM2000 SERIES

by MARKELL

RUN WITH IT!!

White with Pink Trim
TM-2004 – 5 to 10
TM-2005 – 10 ½ to 2
TM-2015 – 2 ½ to 4
M and W Widths

White with Blue Trim
TM-2002 – 5 to 10
TM-2003 – 10 ½ to 2
TM-2013 – 2 ½ to 4
M and W Widths

White with Grey Trim
TM-2000 – 5 to 10
TM-2001 – 10 ½ to 2
TM-2010 – 2 ½ to 4
M and W Widths

TM-2
White with Grey Trim
White with Pink Trim
White with Blue Trim

QUICKLY AVAILABLE FROM STOCK!

MARKELL is committed to the best in therapeutic foot products. With an eye to the future, we have created a true orthopedic sneaker for children.

The TM 2000 Series has the following features:

- Symmetrical straight last.
- Added depth – 3/16" (5mm) deeper than our conventional straight last shoes, to accommodate orthotics, AFO's and internal modifications.
- Extended counters firm enough to provide support and stability.
- Whole and half sizes from Infants' 5 to Youths' 4.
- Widths – A choice of Medium and Wide.
- Removable cushioned insoles.

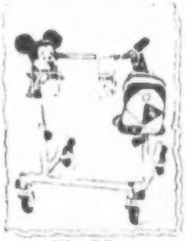
Available From: http://www.markellshoe.com

M.J. MARKELL SHOE CO., INC.

504 Saw Mill River Road, P.O. Box 246 Main Station, Yonkers, N.Y. 10702
Tel: (914) 963-2258 Fax: (914) 963-9293

Circle #85 or visit www.eparent.com/adinfo

Anterior & Posterior Safety Rollers



Safety Roller

- Adult
- Junior
- Pediatric

Custom Sizes Available to Ensure Optimal Fit

Accessories: Variable resistance tabs, Adjustable forearm platforms, IV pole, Oxygen tank holder, Basket & Seat.

Pediatric Seating Positioning Systems

Available in Several Models & Sizes

Embrace Multi-Positioning Stander

Prone Supine and Vertical Positions

MSS Tilt & Recline

Can be used as:

- Floor Sitter
- Hi-Chair
- Booster Chair
- Insert for MSS Traveler Stroller Frame

CALL US AT

(800) 706-9255

about our 60 day FREE EVALUATION PROGRAM

Wenzelite Re/hab

SUPPORTING YOUR PATIENTS

www.wenzelite.com • e-mail: wenzelite@aol.com

Circle #136 or visit www.eparent.com/adinfo

Positive lifestyles

for people with developmental disabilities.

Residential, vocational and day programs are provided in a rural village setting. Residents enjoy community living, and a lifestyle designed to appreciate their individual characteristics. Respite care is also available.

Martha Lloyd

190 West Main • Troy, PA • www.marthalloyd.org • E-mail: mlcs@epix.net

(570) 297-2185, Ext. 268

Circle #87 or visit www.eparent.com/adinfo

Speaking of fun...

Natasha is learning to communicate, but has a long way to go. In the meantime we're learning what she has to say through pictures in her communication book. She's working toward more sophisticated methods of expressing herself, but this gives her a way of speaking to us right now. Every day is an adventure for Natasha, and we don't want to miss a thing.

HEARTSPRING™
SCHOOL

Finding New Ways for Learning

8700 East 29th Street North • Wichita, Kansas 67226
Call 1-800-835-1043
www.heartspring.org

Circle #24 or visit www.eparent.com/adinfo

CROTCHED
MOUNTAIN
OFFERING A LIFELONG ALLIANCE
TO PEOPLE WITH DISABILITIES

PRESIDENT AND CHIEF EXECUTIVE OFFICER

CROTCHED MOUNTAIN FOUNDATION
Greenfield, New Hampshire

Crotched Mountain Foundation (CMF) invites nominations and expressions of interest for the position of President and CEO as a result of the upcoming retirement of its current President.

Situated on a gorgeous mountaintop campus of over 1,400 acres in Greenfield, NH (located 45 minutes from Manchester, NH and two hours from Boston in southern New Hampshire), Crotched Mountain is a premier organization providing education, rehabilitation, medical and community living services for children and adults with disabilities throughout New Hampshire and neighboring states for nearly 50 years. The Greenfield campus is home to the Crotched Mountain School, a residential and day special education facility for 125 children with disabilities, a skilled nursing facility and rehabilitation center for adults with brain injuries, an outpatient clinic that provides a range of medical and rehabilitation services to people with disabilities, a specialty hospital for children, and other service programs. Crotched Mountain also provides care management, housing and rehabilitation services in locations throughout New Hampshire and in northeastern Massachusetts, New York State and Maine. Through its affiliated corporations, CMF serves more than 1,500 children and adults with disabilities annually. CMF has 780 employees and an annual budget in excess of $30 million.

CMF seeks candidates with exceptional leadership skills, a record of professional achievement and management experience in large, diverse organizations, a commitment to the mission of the organization, and who possess both the vision and the strategic mind to chart the future for this unique organization to continue its evolution as a family-centered community resource. A collegial, team oriented management style will be critical to continuing the high performance culture that has been built at CMF. Successful experience in both advocacy and fundraising are strongly preferred. A passion for improving the lives of individuals with disabilities and their families is a must.

CMF has retained the services of Witt/Kieffer, a national executive search firm, to assist in this important search. Nominations and expressions of interest in the position should be directed to:

Emanuel D. Berger and Paul W.H. Bohne
Witt/Kieffer
4550 Montgomery Ave, Suite 615N
Bethesda, MD 20814

Questions and requests for a complete position description can be directed to Paul W.H. Bohne at (301) 654-5070 or Manny Berger at (781) 272-8899 or via e-mail at paulb@wittkieffer.com

Crotched Mountain Foundation
is an equal opportunity employer.

Educational Management Network/Witt/Kieffer

Circle #138 or visit www.eparent.com/adinfo

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #82 or visit www.eparent.com/adinfo

"They are reaching out because they're discovering how."

The Center for
DISCOVERY

The Center for Discovery is certified by the New York State Education Department and the Department of Health, the New York State Office of Mental Retardation and Developmental Disabilities, and Commission on Accreditation of Rehabilitation Facilities (carf).

Imagine a place where children with significant disabilities explore and learn every day. A gentle, natural, accessible and technologically-enhanced environment that meets each child's individual needs.

Are we the right program for your child?

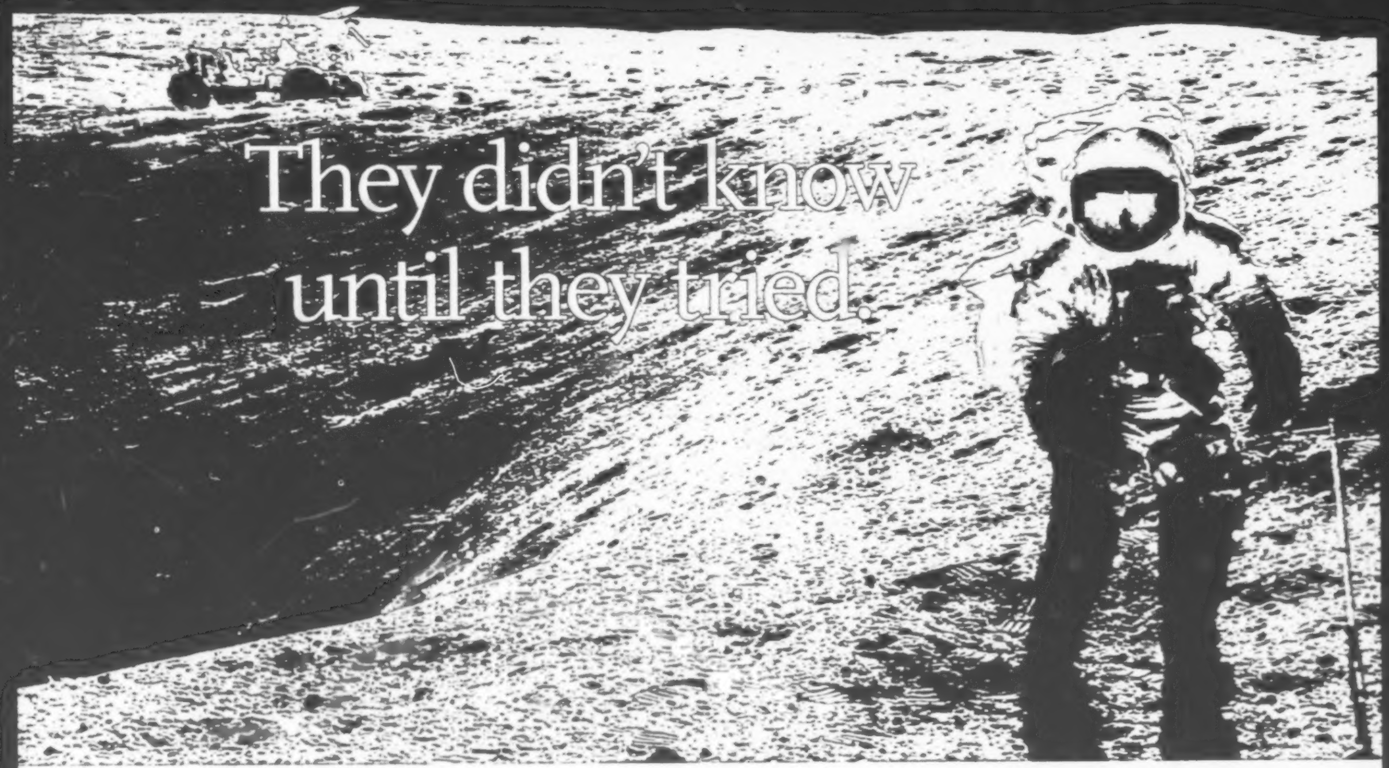
Call our Admissions Office at (845) 794-1400, extension 1444 to arrange a personal tour and see discovery in action.

Ask about our on-site evaluation/assessment packages and our specialized vision services.

Box 840 / Harris, NY 12742
845-794-1400 (Ext. 1444)
Visit our website at
www.thecenterfordiscovery.org

Located less than two hours northwest of New York City in the Catskill Mountains, near Monticello.

Circle #126 or visit www.eparent.com/adinfo


They didn't know until they tried.

If you have severe spasticity, a one-day test can show you a new way to regain control.

Find out more

Even though you're already being treated for severe spasticity, you may not have tried a unique therapy that's helped thousands of individuals with cerebral palsy, brain injury, multiple sclerosis, stroke, or spinal cord injury.

Take the first step

Find out how this therapy can work for you with a one-day screening test dose. Talk to your doctor, or call us today at **800-664-5111 Ext. 275**. You can also log on to **www.spasticity.com** and learn about people just like you who gave this unique therapy a try. And they're very glad they did.

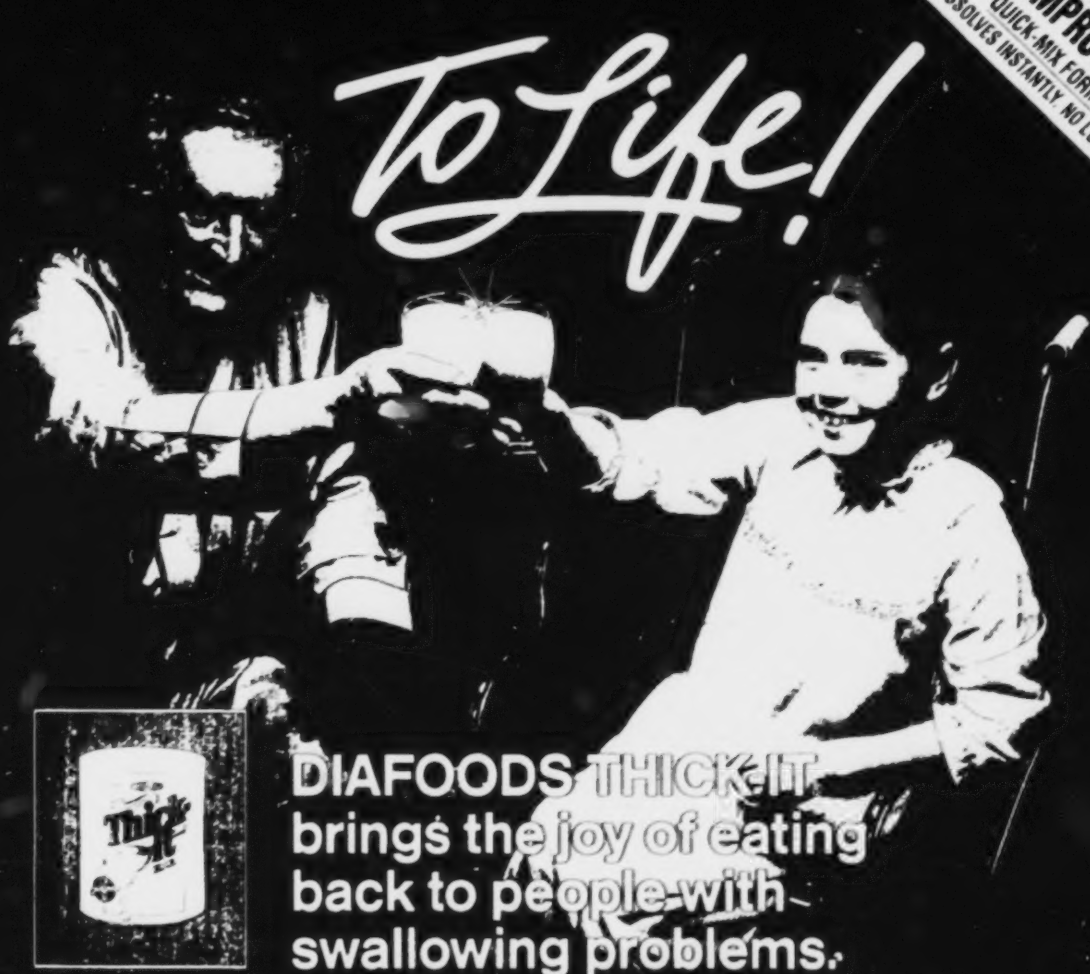
We're here to help: 800-664-5111 Ext. 275
or www.spasticity.com

Medtronic
When Life Depends on Medical Technology

UC200202458 EN

Circle #91 or visit www.eparent.com/adinfo

NEW
IMPROVED
QUICK-MIX FORMULA
DISSOLVES INSTANTLY. NO LUMPING.



DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

Free educational material, call... (800) 333-0003.

The booklet **"Dysphagia, A Review For Health Professionals"** discusses causes, evaluation and treatment of dysphagia.

The pamphlet **"Swallowing Problems"** helps patients and caregivers understand and adapt to dysphagia.

For product literature and advice, a free sample and information where **DIAFOODS THICK-IT** may be purchased, **call... (800) 333-0003.**

©1996 PRECISION FOODS, INC.
2150 N. 15TH AVENUE
MELROSE PARK, IL 60160
TELEPHONE (708) 216-0704
FAX (708) 216-0709

BEST COPY AVAILABLE

Circle #107 or visit www.eparent.com/adinfo

EARLY INTERVENTION

The Individuals with Disabilities Education Act (IDEA) requires all states and territories to provide early intervention and preschool special education for children with disabilities and special healthcare needs. When available, this directory lists these resources for each state or territory:

- Chairpersons of Interagency Coordinating Councils (**ICC**): ICCs include representatives of agencies, service providers, and families. Their role is to advise and provide assistance on early intervention programs and, in some states, preschool services as well.
- Coordinators of infant and toddler programs serving children from birth to age three are known as **Part C** programs.
- Coordinators of preschool special education programs (known as **619** programs) serving children from ages three through five.

These listings are provided by the National Early Childhood Technical Assistance Center (NECTAS, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, 137 E. Franklin St., Suite 500, Chapel Hill, NC 27514; Telephone: (919) 962-2001 (voice); (877) 574-3194 (TDD); Fax: (919) 966-7463; E-mail: nectas@unc.edu; and are current as of November 2001. This information is also available on the NECTAS Web site: http://www.nectas.unc.edu, and is updated on a monthly basis. NECTAS is operating under a no-cost extension from its funding sponsor, the US Department of Educaton.

Using This Directory

When available, e-mail and World Wide Web sites addresses have been included. E-mail addresses are indicated by the symbol ✉. Web sites are listed beginning with their address, so remember to include the standard http:// before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

ICC: Glenn Harger, ICC Chair
United Cerebral Palsy (UCP) of Mobile
3058 Dauphin Square Connector
Mobile, AL 36607
(334) 479-4900
(334) 479-4998 (fax)
✉lgharger1947@aol.com

Part C: Elizabeth D. Prince, Part C Coordinator
Early Intervention Program
2129 East South Boulevard
PO Box 11586
Montgomery, AL 36111-0586
(334) 613-3543
(334) 613-3541 (fax)
✉bdprince@rehab.state.al.us
http://www.rehab.state.al.us/intervention.html

619: Phyllis Mayfield, 619 Coordinator
Program for Exceptional Children
State Department of Education
Gordon Persons Bldng, Rm 3346
PO Box 302101
Montgomery, AL 36130-2101
(334) 242-8114
(334) 242-9192 (fax)
✉phyllism@sdenet.alsde.edu

ALASKA

ICC: Ernie Dummann, ICC Chair
6706 Greenwood Street, #1
Anchorage, AK 99518
(907) 337-6014
✉dualaska@alaska.net

ICC: Vern Gillis, ICC Chair of EI Committee of ICC
8626 Moorland
Anchorage, AK 99502
(907) 243-5698
✉vrgillis@pobox.alaska.net

Part C: Jane Atuk, Part C, Coordinator
Maternal and Child Health
State Department of Health and Social Services
3601 C Street, Suite 934
PO Box 240249
Anchorage, AK 99524-0249
(907) 269-3419
(907) 269-3465 (fax)
✉jane_atuk@health.state.ak.us
http://health.hss.state.ak.us/dph/mcfh/programs/ei-dp.htm

619: Karen Sato, 619 Coordinator
State Department of Education
801 West Tenth Street, Suite 200
Juneau, AK 99801-1894
(907) 465-8702
(907) 465-2806 (fax)
✉karen_sato@eed.state.ak.us

AMERICAN SAMOA

ICC: Saapini Sutuu, Chair
LBJ Tropical Medical Center
American Samoa Hospital Authority
Government of American Samoa
Pago Pago, AS 96799
(684) 633-4929
(684) 633-2167 (fax)

Part C: Julia Lyons, Part C Coordinator
Department of Health
Government of American Samoa
Pago Pago, AS 96799
(684) 633-4929
(684) 633-2167 (fax)
✉hspain5620@hotmail.com

619: Iris Leota, Preschool Contact
Special Education Division
Department of Education
PO Box 4660
Pago Pago, AS 96799
(684) 258-2416
(684) 633-1641 (fax)
✉ifleota@samoatelco.com

ARIZONA

ICC: Ginger Mach Ward, ICC Co-Chair
Southwest Human Dev., Inc.
202 East Earll, Suite 140
Phoenix, AZ 85012
(602) 266-5976
✉gward@swhd.org

ICC: Annabel Rose, Co-Chair, ICC
The Blake Foundation
Children's Achievement Center
330 North Commerce Park Loop, Suite 100
Tucson, AZ 85745
(520) 325-6495, Ext. 112
(520) 327-5414 (fax)
✉larose@theriver.com

Part C: Molly Dries, Part C Coordinator and Exec. Director
AZ Early Intervention Program
Department of Economic Security
3839 North 3rd Street, Suite 304
Site Code #801 A-6
Phoenix, AZ 85012
(602) 532-9960 x113
(602) 200-9820 (fax)
✉lvomm5793@de.state.az.us
http://www.ade.state.az.us/health-safety/earlychildhood/azeip.asp

619: Linda Shields, Coordinator
Division of Special Education
Arizona Department of Education
1535 West Jefferson Street
Phoenix, AZ 85007
(602) 364-4011
(602) 542-5404 (fax)
✉lshield@mail1.ade.state.az.us
http://www.ade.state.az.us/ess/presch/

ARKANSAS

ICC: Ruth Castleberry, ICC Chair
PO Box 10508
Conway, AR 72033
(501) 329-2164
(501) 329-2113 (fax)
✉lfcds01@conwaycorp.net

Part C: Sherrill Archer, Part C Coordinator
DD Services, Department of Human Services
Donaghey Plaza North
7th and Main Streets
PO Box 1437, Slot 2520
Little Rock, AR 72203-1437
(501) 682-8699
(501) 682-8687 (fax)
✉sherrill.archer@mail.state.ar.us
http://www.ark.org/dhs/ddds/ddscomsup.html

619: Sandra Reifeiss, Coordinator
Special Education Section
State Department of Education
#4 Capitol Mall, Room 105-C
Little Rock, AR 72201
(501) 682-4225
(501) 682-5168 (fax)
✉sreifeiss@arkedu.k12.ar.us

BUREAU OF INDIAN AFFAIRS

Part C: Angelita Felix, Lead Education Specialist
Division of School Improvement
OIEP
500 Gold Avenue, SW, Rm. 7202
PO Box 1088
Albuquerque, NM 87103
(505) 248-7527
(505) 248-7546 (fax)
✉angelitafelix@bia.gov

CALIFORNIA

ICC: Raymond M. Peterson, ICC Chair
San Diego-Imperial Counties Development Services, Inc.
4355 Ruffin Road, Suite 206
San Diego, CA 92123-1648
(858) 576-2932
(858) 576-2873 (fax)

Part C: Rick Ingraham, Chief, Children and Family Svcs Branch
Early Start System
Children and Family Services Branch
Dept. of Developmental Services
1600 9th Street, MS 3-12
PO Box 944202
Sacramento, CA 95814
(916) 654-2205
(916) 654-3255 (fax)
✉RIngraha@dds.ca.gov
http://www.dds.ca.gov/EarlyStart/main/ESHome.cfm

619: Walter Olsen, Coordinator
Special Education Division
State Department of Education
515 L Street, Suite 270
Sacramento, CA 95814
(916) 327-4216
(916) 327-3706 (fax)
✉wolsen@cde.ca.gov

COLORADO

ICC: Sandra Scott, ICC Co-Chair
1808 Centennial Road
Fort Collins, CO 80525
(970) 266-1344
(970) 266-6025 (fax)
✉coachsys@earthlink.net

ICC: Steven Smetak, ICC Co-Chair
9051 Hoyt Street
Westminster, CO 80021
(303) 423-1012
(303) 403-4410 (fax)
✉ssmetak@dnvr.uswest.net

Part C: Susan Smith, Part C Coordinator
Prevention Initiatives
Colorado Dept. of Education
201 East Colfax Ave, Room 301
Denver, CO 80203
(303) 866-6709
(303) 866-6662 (fax)
✉smith_s@cde.state.co.us
http://www.cde.state.co.us/earlychildhoodconnections

619: Jane L. Amundson, 619 Coordinator
Prevention Initiatives
Early Childhood Initiatives
Colorado Dept. of Education
201 East Colfax Avenue, Room 306
Denver, CO 80203-1799
(303) 866-6712
(303) 866-6662 (fax)
✉Amundson_J@cde.state.co.us

CONNECTICUT

ICC: Ann Gionet, ICC Chair
12 Dailey Circle
Vernon, CT 06066
(860) 872-7206
✉agionet@snet.net

Part C: Linda Goodman, Part C Coordinator
Birth to Three System
Dept. of Mental Retardation
460 Capitol Avenue
Hartford, CT 06106-1308
(860) 418-6147
(860) 418-6003 (fax)
✉linda.goodman@po.state.ct.us
http://www.birth23.org/

619: Maria Synodi, Coordinator
State Department of Education
25 Industrial Park Road
Middletown, CT 06457
(860) 807-2054
(860) 807-2062 (fax)
✉maria.synodi@po.state.ct.us
http://www.state.ct.us/sde/early/index.htm

DELAWARE

ICC: Beth MacDonald, ICC Chair
35 West Fairfield Drive
Dover, DE 19901
(302) 697-1976
(302) 698-1778 (fax) Note: if busy call voice
✉rcabell@state.de.us

Part C: Rosanne Griff-Cabelli, Part C Coordinator
Division of Management Services
Department of Health and Social Services
1901 North Dupont Highway, Room 204
New Castle, DE 19720
(302) 577-4647
(302) 577-4083 (fax)
✉rcabell@state.de.us

619: Martha Toomey,
619 Coordinator
Dept of Public Instruction
Townsend Building
PO Box 1402
Dover, DE 19903-1402
(302) 739-4667
(302) 739-2388 (fax)
E-✉mtoomey@state.de.us
http://www.doe.state.de.us/exceptional_child/Early Childhood Site/earlychildhoodhome.htm

DISTRICT OF COLUMBIA

ICC: Ruby Gourdine, ICC Chair
Howard University
School of Social Work
601 Howard Place, NW
Washington, DC 20059
(202) 846-4733
(202) 483-9518 (fax)

Part C: Joan Christopher,
Part C Coordinator
Office of Early Childhood Development
DC-EIP Services
717 14th Street, NW, Suite 730
Washington, DC 20002
(202) 727-1839
(202) 727-8166 (fax)
E-✉jchristopher@dhs.dcgov.org

619: Celestine Diggs Smith, 619 Coordinator
DC Public Schools, 6th Floor
Webb School
1375 Mt. Olive Road NE
Washington, DC 20002
(202) 724-3900
(202) 724-4544 (fax)

FLORIDA

ICC: Theodore Granger, President
United Way of Florida
307 East Seventh Avenue, #204
Tallahassee, FL 32303
(850) 681-9292
(850) 681-9137 (fax)
E-✉tgranger@uwof.org

Part C: Co-Coordinators
Janet Evans, Co-Coordinator
Janice Kelley, Co-Coordinator
Monica E. Rutkowski, Co-Coordinator
Early Intervention Unit
Children's Medical Services
Department of Health
2020 Capital Circle SE, BIN # A06
Tallahassee, FL 32399-1700
(850) 245-4444 Ext 2223 (Evans)
(850) 245-4444 Ext 2234 (Kelley)
(850) 245-4221 (Rutkowski)
(850) 414-7350 (fax)
E-✉Janet_Evans@doh.state.fl.us
E-✉janice_kelley@doh.state.fl.us
E-✉monica_rutkowski@doh.state.fl.us
http://www9.myflorida.com/cms/preventdivision/cmseipservices.htm

619: Carla Brown, Coordinator
Carole West, Part C Liaison
Department of Education
Bureau of Instructional Support and Community Services
325 West Gaines Street, Suite 601
Tallahassee, FL 32399-0400
(850) 488-1106
(850) 922-7088 (fax)
E-✉brownc3@mail.doe.state.fl.us
E-✉westc@mail.doe.state.fl.us

GEORGIA

ICC: Walter Black, ICC Chair
5097 Vixen Court
Acworth, GA 30101
(770) 975-1173
E-✉walterblack@mindspring.com

Part C: Stephanie Moss,
Part C Coordinator
Wendy Sanders, Director
Office of Children with Special Needs, Babies Can't Wait Program
Division of Public Health,
Family Health Branch
Department of Human Resources
2 Peachtree Street, NE,
Suite 11-206
Atlanta, GA 30303-3186
(404) 657-2721 (Moss)
(404) 657-2727 (Sanders)
(404) 657-2763 (fax)
E-✉skmoss@dhr.state.ga.us
E-✉wsanders@dhr.state.ga.us
http://www.ph.dhr.state.ga.us/programs/bcw/index.shtml

619: Sheila Langston,
Low Incidence Coordinator
Department for Exceptional Students
State Department of Education
1870 Twin Towers East
Atlanta, GA 30334-5010
(404) 657-9955
(404) 651-6457 (fax)
E-✉slangsto@doe.k12.ga.us

GUAM

ICC: Mamie C. Balajadia,
ICC Chair
Department of Mental Health and Substance Abuse
790 Gov Carlos Camacho Road
Tamuning, GU 96911
(671) 647-5440
(671) 649-6948 (fax)

Part C: Elaine Eclavea,
Part C Administrator
Guam UAP
College of Education,
UOG Station
303 University Drive
Mangilao, GU 96923
(671) 735-2414
(671) 735-2439 (fax)
E-✉eeclavea@ite.net

Part C: Vince Leon Guerrero,
Associate Superintendent
Division of Special Education
Department of Education
PO Box DE
Agana, GU 96932
(671) 475-0549
(671) 475-0562 (fax)
E-✉doesped1@ite.net
http://www.nectas.unc.edu/pubaware/CFPacific

619: Vince Leon Guerrero,
Associate Superintendent
Division of Special Education
Department of Education
PO Box DE
Agana, GU 96932
(671) 475-0549
(671) 475-0562 (fax)
E-✉doesped1@ite.net
http://www.nectas.unc.edu/pubaware/CFPacific

HAWAII

ICC: Ha'aheo Mansfield,
ICC Chair
51-544 A-1 Kamehameha Highway
Kaaawa, HI 96730
(808) 237-8190

Part C: Sue Brown,
Part C Coordinator
Zero-to-3 Hawaii Project
Department of Health
Pan Am Building
1600 Kapiolani Boulevard,
Suite 1401
Honolulu, HI 96814
(808) 957-0066
(808) 946-5222 (fax)
E-✉suebrown@fhsd.health.state.hi.us

619: Michael Fahey, 619 Coordinator/CSPD Coordinator
Special Needs Branch
Hawaii Department of Education
Building C, Room 102
637 18th Avenue
Honolulu, HI 96816
(808) 733-4840
(808) 733-4475 (fax)
E-✉michael_fahey/SPED/HIDOE@notes.k12.hi.us

IDAHO

ICC: Kim Hegg-James,
ICC Co-Chair
3322 E. Redstone Drive
Boise, ID 83712
(208) 368-9870
E-✉kimhjames@earthlink.net

ICC: Russ Henderson,
ICC Co-Chair
107 Richardson Avenue
Lewiston, ID 83501
Phone: (208) 799-1620
E-✉russanddebh@home.com

Part C: Mary Jones,
Part C Project Manager
Infant/Toddler Program
Dept. of Health and Welfare
450 West State Street, 5th Floor
PO Box 83720
Boise, ID 83720-0036
(208) 334-5523
(208) 334-6664 (fax)
E-✉jonesm@dhw.state.id.us
http://www2.state.id.us/dhw/InfToddler/index.htm

619: Jane Zornik, 619 Coordinator
Bureau of Special Education
Idaho Department of Education
650 West State Street
PO Box 83720
Boise, ID 83720-0027
(208) 332-6915
(208) 334-4664 (fax)
E-✉jzornik@sde.state.id.us
http://www.sde.state.id.us/SpecialEd/

ILLINOIS

ICC: Anne Shannon, ICC Chair
PARC
9901 Derby Lane
Westchester, IL 60154
(708) 547-3550 Ext 3597
(708) 547-4067 (fax)
E-✉parcassn@aol.com

Part C: Janet Gully, Part C
Acting Bureau Chief
Department of Human Services
Bureau of Early Intervention
623 East Adams, 2nd Floor
PO Box 19429
Springfield, IL 62794-9429
(217) 782-1981
(217) 524-6248 (fax)
E-✉dhsvr50@dhs.state.il.us
http://www.state.il.us/agency/dhs/eisnp.html

619: Pam Reising-Rechner, 619
Principal Consultant
Division of Early Childhood Education
State Board of Education
100 North First Street, E-230
Springfield, IL 62777-0001
(217) 524-4835
(217) 785-7849 (fax)
E-✉preisang@smtp.isbe.state.il.us
http://www.isbe.state.il.us/

INDIANA

ICC: Denise Arland, ICC Chair
807 Whispering Trail
Greenfield, IN 46140
(317) 462-0653
(317) 467-0814 (fax)
E-✉dlarland@home.com

Part C: Maureen Greer,
Part C Director
First Steps
Bureau of Child Development
Division of Family and Children
402 West Washington Street,
#W-386, MS02
Indianapolis, IN 46204
(317) 233-9229
(317) 232-7948 (fax)
E-✉mgreer@fssa.state.in.us
http://www.state.in.us/fssa/first_step/

619: Sheron Cochran,
619 Coordinator
Division of Special Education
Indiana Department of Education
State House, Room 229
Indianapolis, IN 46204-2798
(317) 232-0567
(317) 232-0589 (fax)
E-✉scochran@doe.state.in.us

IOWA

ICC: Georgia Woodard, ICC Chair
202 2nd Street South East
Altoona, IA 50009
(515) 967-5622
E-✉georgwood@home.com

Part C: Lynda Pletcher,
Coordinator
Early Access/Part C
Bureau of Children, Family, and Community Services
Grimes State Office Bldg, 3rd Fl.
Des Moines, IA 50319-0146
(515) 281-7145
(515) 242-6019 (fax)
E-✉lynda.pletcher@ed.state.ia.us

619: Dee Gethmann, Early Childhood Specialist
Bureau of Children, Family, and Community Services
State Department of Education
Grimes State Office Building
Des Moines, IA 50319-0146
(515) 281-5502
(515) 242-6019 (fax)
E-✉dee.gethmann@ed.state.ia.us

KANSAS

ICC: Sharon Hixson, ICC Chair
714 Ballinger
Garden City, KS 67846
(620) 275-0291
(620) 275-0364 (fax)
E-✉turlearning@aol.com

Part C: Carolyn Nelson,
Coordinator
Infant Toddler Program
Department of Health and Environment
Landon State Office Building
900 SW Jackson, Room 1005
Topeka, KS 66612-1290
(785) 296-6135
(785) 296-8626 (fax)
E-✉cnelson@kdhe.state.ks.us
http://www.kdhe.state.ks.us/bcyf/cds/its/index.html

619: Marnie Campbell,
Early Childhood Coordinator
Special Education Administration
Department of Education
120 East 10th Avenue
Topeka, KS 66612-1182
(785) 296-1944
(785) 296-1413 (fax)
E-✉mcampbell@ksde.org
http://www.ksbe.state.ks.us/specialeducation.html

KENTUCKY

ICC: Deborah Watson, ICC Chair
Child Development Centers of the Bluegrass
465 Springhill Drive
Lexington, KY 40503
(859) 278-0549
(859) 277-0807 (fax)
E-✉cdcb@gte.net

Part C: Germaine O'Connell,
Part C Coordinator
First Steps Program
Division of Mental Retardation
Department of MH
and MR Services
100 Fair Oaks Lane, 4E-E
Frankfort, KY 40621-0001
(502) 564-7722
(502) 564-0438 (fax)
E-✉germaine.o'connell@mail.state.ky.us
http://brcee.coop.k12.ky.us/firststeps12/firststeps/fshome.htm

619: Barbara Singleton,
619 Coordinator
Division of Preschool Services
Department of Education
1711 Capitol Plaza Tower
Frankfort, KY 40601
(502) 564-7056
(502) 564-6952 (fax)
E-✉bsinglet@kde.state.ky.us
http://www.kde.state.ky.us/

LOUISIANA

ICC: Rep. Melinda Schwegmann,
ICC Chair
6305 Elysian Fields, Suite 200
New Orleans, LA 70122
(504) 286-0717
(504) 286-1305 (fax)
E-✉larep098@iamerica.net

EARLY INTERVENTION

Part C: Evelyn Johnson, Section
Supervisor Part C and ECSE
Division of Special Populations
State Department of Education
PO Box 94064
Baton Rouge, LA 70804-9064
(225) 342-3730
(225) 342-5297 (fax)
✉edjohnson@mail.doe.state.la.us
http://www.doe.state.la.us/DOE/
specialpop/ITPDisab/ITPDhome.asp

619: Donna L. Martin,
Program Coordinator
State Department of Education
Division of Special Populations
Preschool Special Education
PO Box 94064
Baton Rouge, LA 70802
(225) 342-3730
(225) 342-5297 (fax)
✉Dmartin@mail.doe.state.la.us

MAINE

ICC: Jean Eaton, ICC Chair
CDS Lincoln County
PO Box 1114
Damariscotta, ME 04543
(207) 563-1411
(207) 563-6312 (fax)

Part C and 619:
Joanne C. Holmes, 619 and
Part C Coordinator
Child Development Services
Department of Education
State House Station #146
Augusta, ME 04333
(207) 624-6660
(207) 624-6661 (fax)
✉jaci.holmes@state.me.us
http://www.state.me.us/
education/speced/cdsstaff.htm

MARSHALL ISLANDS

619: Wanbwe Mesubed,
Preschool Director
Ministry of Education
Republic of the Marshall Islands
PO Box 3179
Majuro, MH 96960
(692) 625-5261
(692) 625-3861 (fax)

MARYLAND

ICC: Gilbert Armstrong,
ICC Co-Chair
9208 Roxanne Drive
Lanham, MD 20706
(301) 981-8256
✉spider915@aol.com

ICC: Renee Wachtel,
ICC Co-Chair
Developmental Pediatrics
School of Medicine
University of Maryland
630 West Fayette Street,
Room 5686
Baltimore, MD 21201
(410) 706-3542
(410) 706-0835 (fax)
✉rwachtel@peds04.ab.umd.edu

Part C: Deborah Metzger,
Branch Chief, Part C Coordinator
MD Infant/Toddler/Preschool
Services Division
Division of Special Education/
Early Intervention Services
State Department of Education
200 West Baltimore Street
Baltimore, MD 21201
(410) 767-0261
(410) 333-2661 (fax)
✉dmetzger@msde.state.md.us
http://www.msde.state.md.us/
programs/infantsandtoddlers/
earlier.html

619: Nancy Vorobey, Coordinator
Infant/Toddler Preschool Services
Division of Special Education
State Department of Education
200 West Baltimore Street
Baltimore, MD 21201
(410) 767-0234
(410) 333-2661 (fax)
✉nvorobey@msde.state.md.us

MASSACHUSETTS

ICC: Barbara Prindle Eaton,
ICC Chair
Cape Cod & Islands Early
Childhood Intervention Program
83 Pearl Street
Hyannis, MA 02601
(508) 775-6998
(508) 790-4298 (fax)
✉bpeaton@cccdp.org

Part C: Ron Benham,
Part C Coordinator and Dir. of EI
Early Intervention Services
Department of Public Health,
4th Floor
250 Washington Street
Boston, MA 02108-4619
(617) 624-5969
(617) 624-5990 (fax)
✉ron.benham@state.ma.us
http://www.state.ma.us/dph/
shcn/ei.htm

619: Fran Basche,
619 Co-Coordinator
Early Learning Services
MA Department of Education
350 Main Street
Malden, MA 02148-5023
(781) 338-6351
(781) 338-3370 (fax)

619: Elisabeth Schaefer,
Director Early Learning Services
MA Department of Education
350 Main Street
Malden, MA 02148-5023
(781) 338-6357
(781) 338-3380 (fax)
✉eschaefer@doe.mass.edu
http://www.doe.mass.edu/

619: Donna Traynham,
619 Co-Coordinator
Early Learning Services
MA Department of Education
350 Main Street
Malden, MA 02148-5023
(781) 338-6372
(781) 338-3370 (fax)

MICHIGAN

ICC: Denise McGarr,
ICC Co-Chair
16165 Washburn
Detroit, MI 48221
(313) 864-7393

ICC: Mac Miller, ICC Co-Chair
Livingston County CMH Services
2280 East Grand River
Howell, MI 48843
(517) 546-4126
(517) 546-1300 (fax)
✉macmiller@htonline.com

Part C: Vanessa Winborne,
Part C Coordinator
Early On Michigan
Office of Special Education
and EI Services
Michigan Dept of Education
PO Box 30008
Lansing, MI 48909
(517) 335-4865
(517) 373-7504 (fax)
✉winbornev@state.mi.us

619: Benjamin Hamilton,
619 Coordinator
Office of Special Ed and EI Svcs
Michigan Dept. of Education
PO Box 30008
Lansing, MI 48909
(517) 241-1820
(517) 241-3690 (fax)
✉hamiltonben@state.mi.us

MICRONESIA, FED. STATES OF

619: Makir Keller, Special Ed
Administrator
Div. of Education
Dept. of Health, Education and
ocial Affairs
PO Box PS87, Pohnpei State
Palikir, Pohnpei, FM 96941
(691) 320-2302
(691) 320-5500 (fax)
✉ mkeller@mail.fm

MINNESOTA

ICC: Wes Mattsfield, ICC Chair
P.O. Box 308
Esko, MN 55733
(218) 879-3321 Ext.118
(218) 879-7097 (fax)
Note: attn: Norm Swett
✉wesmatts@computerpro.com

Part C: Jan Rubenstein,
Part C Coordinator
Interagency Early
Intervention Program
Department of Children,
Families and Learning
1500 Highway 36 West
Roseville, MN 55113-4266
(651) 582-8436
(651) 582-8494 (fax)
✉jan.rubenstein@state.mn.us
http://cfl.state.mn.us/ecfi/
partc.htm

619: Lisa Backer,
619 Co-Coordinator
Department of Children,
Families and Learning
1500 Highway 36 West
Roseville, MN 55113-4266
(651) 582-8473
(651) 582-8494 (fax)
✉Lisa.Backer@state.mn.us
http://cfl.state.mn.us/ecfi/

619: Michael Eastman, Early
Childhood Spec Ed Specialist
Department of Children,
Families and Learning
1500 Highway 36 West
Roseville, MN 55113-4266
(651) 582-8343
(651) 582-8494 (fax)
✉michael.eastman@state.mn.us
http://cfl.state.mn.us/ecfi/

MISSISSIPPI

ICC: Louis Aldridge, ICC Co-Chair
PO Box 2611
Tupelo, MS 38803
(601) 842-3569
✉laldridge@dixie-net.com

ICC: Rep. John Moore,
ICC Co-Chair
101 Shiloh Road
Brandon, MS 39042
(601) 366-4100

Part C: Roy Hart,
Part C Coordinator
Infant and Toddler Program
Mississippi State
Department of Health
2423 North State Street,
Room 105A
PO Box 1700
Jackson, MS 39215-1700
(601) 576-7427
(601) 576-7540 (fax)
✉rhart@msdh.state.ms.us
http://www.msdh.state.ms.us/
OPHS/EARLYINT/home.htm

619: Dot Bowman,
619 Coordinator
Office of Special Education
Mississippi Dept. of Education
359 North West Street
PO Box 771
Jackson, MS 39205-0771
(601) 359-3498
(601) 359-2198 (fax)
✉dbowman@mdek12.state.ms.us

MISSOURI

ICC: Sharon Hailey, ICC Co-Chair
Director/Programming
Developmental Center
of the Ozarks
1545 East Pythian
Springfield, MO 65802
(417) 831-1545
(417) 865-7603 (fax)

ICC: Anne Marie Wells,
ICC Co-Chair
605 West 30th
Higginsville, MO 64037
(660) 584-3785
(660) 584-5781 (fax)
✉tlwells@ctcis.net

Part C: Paula Goff, Part C
Coordinator and Director
Early Childhood Special Education
Department of Elementary and
Secondary Education
State Department of Education
PO Box 480
Jefferson City, MO 65102-0480
(573) 751-0185
(573) 526-4404 (fax)
✉pgoff@mail.dese.state.mo.us
http://www.dese.state.mo.us/divs
peced/earlyintervention.html

MONTANA

ICC: Kelly Johnson, ICC Chair
945 4th Avenue
East Kalispell, MT 59901
(406) 755-2425
(406) 755-2426 (fax)
✉kjohnson@wmcdc.org

Part C: Vicki LaFond-Smith,
Part C Coordinator
Developmental Disabilities
Program
Department of Public Health
and Human Services
PO Box 4210
Helena, MT 59604-4210
(406) 444-7382
(406) 444-0230 (fax)
✉vlafond-smith@state.mt.us
http://www.dphhs.state.mt.us/
dsd/index.htm

619: Daniel McCarthy,
Preschool/Monitoring Specialist
Division of Special Education
Office of Public Instruction
PO Box 202501
Helena, MT 59620-2501
(406) 444-4425
(406) 444-3924 (fax)
✉danmcc@state.mt.us
http://www.metnet.state.mt.us/
main.html

NEBRASKA

ICC: Linda B. Shafer, ICC Chair
State Farm Insurance
West Central Office
222 South 84th Street
P.O. Box 82542
Lincoln, NE 68501-2542
(402) 327-5216
✉linda.shafer.adam@
statefarm.com

Part C: Charlotte Lewis,
Part C Co-Coordinator
Nebraska Department of Health
and Human Services
Special Services for Children and
Adults (Early Intervention)
301 Centennial Mall South
PO Box 95044
Lincoln, NE 68509
(402) 471-9329
(402) 471-6252 (fax)
✉charlie.lewis@hhss.state.ne.us
http://www.nde.state.ne.us/ECH/
EARLY/echp.htm

Part C: Joan Luebbers,
Part C Consultant
Special Education Office
Nebraska Dept of Education
301 Centennial Mall South
PO Box 94987
Lincoln, NE 68509-2471
(402) 471-2463
(402) 471-5022 (fax)
✉ luebbers@nde.state.ne.us

619: Jan Thelen, 619 Coordinator
Special Education Office
Nebraska Dept of Education
301 Centennial Mall South
PO Box 94987
Lincoln, NE 68509-4987
(402) 471-4319
(402) 471-5022 (fax)
✉jthelen@nde.state.ne.us

NEVADA

ICC: Keith Allred, ICC Chair
Nevada Department of Education
700 East 5th Street, Suite 113
Carson City, NV 89701
(775) 687-9170
(775) 687-9123 (fax)
✉kallred@nsn.k12.nv.us

Part C: Janelle Mulveron,
Clinical Program Manager
Community Connections
Department of Human Resources
3987 South McCarran Boulevard
Reno, NV 89502
(775) 688-2284
(775) 688-2558 (fax)
✉jamulven@dcfs.state.nv.us
http://www.nvcommunityconnections.com/programs/agencies.php?serviceid=4&programid=3

619: Keith Allred,
619 Coordinator
Educational Equity
Nevada Department of Education
700 East 5th Street, Suite 113
Carson City, NV 89701
(775) 687-9170
(775) 687-9123 (fax)
✉kallred@nsn.k12.nv.us

NEW HAMPSHIRE

ICC: Deborah Bennis,
ICC Parent Chair
Parent Information Center
PO Box 2405
Concord, NH 03302-2405
(603) 224-7005
(603) 224-4365 (fax)
✉dbennis@ttlc.net

Part C: Carolyn Stiles,
Part C Coordinator/Program
Specialist Family Centered Early
Supports and Services
Department of Health
and Human Services
Div. of Developmental Services
105 Pleasant Street
Concord, NH 03301
(603) 271-5122
(603) 271-5166 (fax)
✉cstiles@dhhs.state.nh.us
http://www.state.nh.us/nhsl/frc/eitable.html

619: Ruth Littlefield,
619 Coordinator
Bureau of Early Learning
NH Department of Education
State Office Park, South
101 Pleasant Street
Concord, NH 03301
(603) 271-2178
(603) 271-1953 (fax)
✉rlittlefield@ed.state.nh.us

NEW JERSEY

ICC: William S. Agress,
ICC Chair
32 Pagoda Court
Lawrenceville, NJ 08648
(609) 895-0099
(609) 895-9592 (fax)

ICC: Antoinette Spiotta,
ICC Vice Chair
Montclair State University
Montclair, NJ 07043
(973) 655-4255
(973) 655-5155 (fax)
✉spiottaa@mail.montclair.edu

Part C: Terry Harrison,
Part C Coordinator
Early Intervention Program
Department of Health
and Senior Services
Division of Family Health Services
PO Box 364
Trenton, NJ 08625-0364
(609) 777-7734
(609) 292-0296 (fax)
✉Terry.Harrison@doh.state.nj.us
http://www.njeis.org/

619: Barbara Tkach,
619 Coordinator
Office of Special Ed Programs
CN 500
Riverview Executive
Plaza Building 100
Trenton, NJ 08625
(609) 984-4950
(609) 292-5558 (fax)
✉btkach@doe.state.nj.us
http://www.state.nj.us/education/

NEW MEXICO

ICC: Sallie Van Curen, ICC Chair
Parents Reaching Out (PRO)
1000 A Main Street NW
Los Lunas, NM 87031
(505) 865-3700
(505) 865-3737 (fax)
✉svancuren@aol.com

Part C: Cathy Stevenson,
Part C Coordinator
Long Term Services Division
Department of Health
1190 St. Francis Drive
PO Box 26110
Santa Fe, NM 87502-6110
(505) 827-0119
(505) 827-2455 (fax)
✉cstevens@doh.state.nm.us
http://www.health.state.nm.us/ltsd/fit/index.html

Part C: Gloria Yepa,
Education Specialist
Division of School Improvement
OIEP
500 Gold Avenue, SW,
Room 7202
PO Box 1088
Albuquerque, NM 87103
(505) 248-7451
(505) 248-7546 (fax)
✉gloriayepa@bia.gov

619: Eunice Esparza,
619 Co-Coordinator
Special Education Unit
State Department of Education
300 Don Gaspar Avenue
Santa Fe, NM 87501-2786
(505) 827-5878
(505) 827-6791 (fax)
✉eesparza@sde.state.nm.us

619: Angelita Felix,
Lead Education Specialist
Division of School Improvement
OIEP
500 Gold Avenue, SW,
Room 7202
PO Box 1088
Albuquerque, NM 87103
(505) 248-7527
(505) 248-7546 (fax)
✉angelitafelix@bia.gov

619: Maria Landazuri,
619 Co-Coordinator
Special Education Unit
State Department of Education
300 Don Gaspar Avenue
Santa Fe, NM 87501-2786
(505) 827-6788
(505) 827-6791 (fax)
✉mlandazuri@sde.state.nm.us

619: Gloria Yepa,
Education Specialist
Division of School Improvement
OIEP
500 Gold Avenue, SW,
Room 7202
P.O. Box 1088
Albuquerque, NM 87103
(505) 248-7451
(505) 248-7546 (fax)
✉gloriayepa@bia.gov

NEW YORK

ICC: Thomas Roach, ICC Chair
Ulster County Social Services
7 Cicero Avenue
New Paltz, NY 12561
(914) 255-1713
(914) 255-3202 (fax)

Part C: Donna Noyes, Director
Early Intervention Program
State Department of Health
Corning Tower, Room 208
Empire State Plaza
Albany, NY 12237-0618
(518) 473-7016
(518) 473-8673 (fax)
✉dmn02@health.state.ny.us
http://www.health.state.ny.us/nysdoh/eip/index.htm

619: Erlinda Rejino,
619 Coordinator
NYS Education Department
1 Commerce Plaza Room 1624
Albany, NY 12234
(518) 473-0170
(518) 486-4154 (fax)
✉erejino@mail.nysed.gov

NORTH CAROLINA

ICC: Mary Boat, ICC Co-Chair
Department of Human Services
Western Carolina University
Cullowhee, NC 28723
(828) 227-7310
(828) 227-7388 (fax)
✉m.boat@wcu.edu

ICC: Azell Reeves, ICC Co-Chair
P.O. Box 36324
Greensboro, NC 27416
(336) 334-7041
(336) 334-7674 (fax)
✉reevesi@ncat.edu

Part C: Duncan Munn,
Program Manager
Department of Public Health
Early Intervention Branch, DHHS
Womens and Childrens
Health Section
1020 Richardson Drive,
Royster Building
2302 Mail Service Center
Raleigh, NC 27699-2302
(919) 715-7500 Ext 233
(919) 733-3075 (fax)
✉duncan.munn@ncmail.net
http://www.dhhs.state.nc.us/dcd/icc_par.htm

619: Kathy Baars,
619 Coordinator
Exceptional Children Division
Department of Public Instruction
301 North Wilmington Street
Raleigh, NC 27601-2825
(919) 807-3994
(919) 807-3998 (fax)
✉kbaars@dpi.state.nc.us
http://www.dpi.state.nc.us/

NORTH DAKOTA

ICC: Brent Askvig, ICC Chair
Associate Professor
of Special Education
Assistant to Dean
of the Graduate School
Minot State University
Minot, ND 58707
(701) 858-3052
(701) 858-3021 (fax)
✉askvig@warp6.cs.misu.nodak.edu

Part C: Debra Balsdon,
Part C Coordinator
Developmental Disabilities Unit
Department of Human Services
600 South 2nd Street, Suite 1A
Bismarck, ND 58504-5729
(701) 328-8936
(701) 328-8969 (fax)
✉sobald@state.nd.us

619: Marilyn Brucker,
619 Coordinator
Special Education Division
Department of Public Instruction
600 E Boulevard Avenue
Bismarck, ND 58505-0440
(701) 328-2714
(701) 328-4149 (fax)
✉mbrucker@mail.dpi.state.nd.us

NORTHERN MARIANA ISLANDS

Part C and 619: Suzanne Lizama,
Coordinator
CNMI Public Schools
PO Box 1370 CK
Saipan, MP 96950
(670) 664-3754
(670) 664-3796 (fax)
✉slizama@gtepacifica.net

OHIO

ICC: Kimberly Christensen,
ICC Co-Chair
503 McKinley Drive
Bowling Green, OH 43402
(419) 372-7299
✉kchris@bgnet.bgsu.edu

ICC: Sonya Oppenheimer,
ICC Co-Chair
Director, Cincinnati Center for
Developmental Disorders
3333 Burnet Avenue
Cincinnati, OH 45229-3039
(513) 636-8383
✉oppes0@chmcc.org

Part C: Steve Gassman,
Interim Part C Coordinator
Bureau of EI Services
State Department of Health
PO Box 118
Columbus, OH 43266-0118
(614) 644-8389
(614) 728-9163 (fax)
✉sgassman@gw.odh.state.oh.us
http://www.odh.state.oh.us/ODHPrograms/EI/earlyint1.htm

619: Edith Greer,
619 Coordinator Division of Early
Childhood Education
Department of Education
25 South Front Street, Third Floor
Columbus, OH 43215-4183
(614) 466-0224
(614) 728-3223 (fax)
✉edith.greer@ode.state.oh.us
http://www.ode.state.oh.us

OKLAHOMA

ICC: Candye Chavez, ICC Chair
PO Box 12501
Oklahoma City, OK 73157-2501
(405) 440-2538
(405) 789-1662 (fax)
✉cchavez@putnamcityschools.org

Part C: Mark Sharp,
Part C Coordinator
Special Education Office,
Department of Education
Oliver Hodge Memorial
Education Bldg, 4th Floor
2500 North Lincoln Boulevard
Oklahoma City, OK 73105-4599
(405) 521-4880
(405) 522-3503 (fax)
✉mark_sharp@mail.sde.state.ok.us
http://sde.state.ok.us/pro/ei.html

619: Amber Villines-Hackney,
619 Coordinator
Special Education Services
State Department of Education
2500 North Lincoln Boulevard,
Room 411
Oklahoma City, OK 73105-4599
(405) 521-3351 Ext 4867
(405) 522-3503 (fax)
✉amber_villines-hackney@mail.sde.state.ok.us
http://sde.state.ok.us/default.html

OREGON

ICC: Judy Newman, ICC Chair
Early Childhood CARES Program
1859 East 15th Avenue
Eugene, OR 97403
(541) 346-2639
(541) 346-2636 (fax)
✉rtn@oregon.uoregon.edu

Part C: Diana Allen,
Part C Coordinator
Early Intervention /Early
Childhood Special Education
Oregon State Dept. of Education
Public Services Building
255 Capitol Street NE
Salem, OR 97310-0203
(503) 378-3600 Ext 2338
(503) 373-7968 (fax)
✉diana.allen@STATE.OR.US
http://www.ode.state.or.us/sped/spedareas/eiesce/eiecse2.htm

619: Nancy Johnson-Dorn,
619 Coordinator
Special Education Programs
State Department of Education
Public Service Building
255 Capitol Street NE
Salem, OR 97310-0203
(503) 378-3600 Ext 2339
(503) 373-7968 (fax)
✉nancy.johnson-dorn@state.or.us
http://www.ode.state.or.us/

EARLY INTERVENTION

PALAU

ICC: Gillian Johannes,
ICC Chair Special Education
Advisory Council
Republic of Palau
PO Box 716
Koror, Palau, PW 96940
(680) 488-2318
(680) 488-1211 (fax)

Part C: Elizabeth Watanabe,
Coordinator
Bureau of Education
Republic of Palau
PO Box 189
Koror, Palau, PW 96940
(680) 488-2537
(680) 488-2830 (fax)

619: Evans Imetengel,
Special Education Director
Special Education
Bureau of Education
Republic of Palau
PO Box 278
Koror, Palau, PW 96940
(680) 488-2568
(680) 488-2830 (fax)
✉spedcor@palaunet.com

PENNSYLVANIA

ICC: Kathy Brill, ICC Chair
Parent to Parent of PA
6340 Flank Drive, Suite 600
Harrisburg, PA 17112
(717) 540-4722
(717) 657-5983 (fax)
✉ksbrill@aol.com
http://www.eita-pa.org

Part C: Maureen Cronin,
Part C Coordinator
Division of Program
Implementation
Office of Mental Retardation
Department of Public Welfare
PO Box 2675
Harrisburg, PA 17105-2675
(717) 783-7213
(717) 772-0012 (fax)
✉mshankweil@state.pa.us
http://www.dpw.state.pa.us/
omr/omrei.asp

619: Esther Beck,
Special Education Advisor
Bureau of Special Education
Department of Education
333 Market Street, 7th Floor
Harrisburg, PA 17126-0333
(717) 783-6889
(717) 783-6139 (fax)

619: Richard Price, Director
Bureau of Special Education
Department of Education
333 Market Street, 7th Floor
Harrisburg, PA 17126-0333
(717) 783-6882
(717) 783-6139 (fax)
✉rprice@state.pa.us

PUERTO RICO

ICC: Ana Navarro, ICC Chair
Calle Francisco Sein #503
Floral Park
Hato Rey, PR 00917
(787) 759-6546
(787) 759-6719 (fax)

Part C: Naydamar Perez de Otero,
Coordinator
Part C Program
Department of Health
Office of the Secretary
Call Box 70184
San Juan, PR 00936
(787) 274-5659
(787) 274-3301 (fax)

619: Myrta Reyes,
Director for Early Childhood
Special Education Programs
GPO Box 759
Hato Rey, PR 00919
(787) 759-7228
(787) 753-7691 (fax)

RHODE ISLAND

ICC: Dawn Wardyga,
ICC Co-Chair
RI Parent Information Network
175 Main Street
Pawtucket, RI 02860
(401) 727-4144 Ext.58
(401) 727-4040 (fax)
✉familyvoices@ripin.org
http://www.ripin.org

Part C: David Hamel,
Administrator for EI Services
Rhode Island Dept. of Health
3 Capitol Hill
Providence, RI 02908-5097
(401) 222-4632
(401) 222-1442 (fax)
✉daveh@doh.state.ri.us
http://www.health.state.ri.us/
family/bookmark.pdf

619: Amy Cohen,
Preschool Grant Coordinator
Office Integrated Social Services
Department of Education
Shepherd Building
255 Westminister Road
Providence, RI 02903-3400
(401) 222-4600 Ext.2408
(401) 222-4979 (fax)
✉abcohen@ride.ri.net

SOUTH CAROLINA

ICC: Susanna Duckworth,
ICC Chair
Winthrop University
232 O Withers Building
Rock Hill, SC 29733
(803) 323-2453
(803) 323-2585 (fax)
✉duckworths@winthrop.edu

Part C: David Steele,
Part C Coordinator
BabyNet
Bureau of Maternal
and Child Health
Department of Health and
Environmental Control
Mills/Jarrett Complex,
Box 101106
Columbia, SC 29211
(803) 898-0591
(803) 898-0613 (fax)
✉d.k.steele@worldnet.att.net
http://www.scbabynet.org/

619: Norma Donaldson-Jenkins,
619 Coordinator
Programs for Exceptional Children
State Department of Education
Rutledge Building
1429 Senate Street
Columbia, SC 29201
(803) 734-8811
(803) 734-4824 (fax)
✉njenkins@sde.state.sc.us

SOUTH DAKOTA

ICC: Joanne Wounded Head,
ICC Chair
SD UAP
School of Medicine
414 East Clark Street
Vermillion, SD 57069
(605) 677-5311
(605) 677-6274 (fax)
✉jwounded@usd.edu

Part C: Barb Hemmelman,
Education Program
Assistant Manager
Office of Special Education
700 Governors Drive
Pierre, SD 57501
(605) 773-4478
(605) 773-6846 (fax)
✉barb.hemmelman@state.sd.us
http://www.state.sd.us/deca/SPECIAL/oseprogs/Birthto3.htm

619: Jan Elsing, 619 Coordinator
Office of Special Education
700 Governors Drive/
Kneip Building
Pierre, SD 57501
(605) 773-3678
(605) 773-3782 (fax)
✉jan.elsing@state.sd.us

TENNESSEE

ICC: Lynne F. Harmon,
Interim ICC Chair
Parent-Child Services Group, Inc.
1225 E. Weisgarber Rd.
Suite 180 South
Knoxville, TN 37909
(865) 584-5558 Ext.101
(865) 584-6607 (fax)
✉lynneh@parent-childservices.com

Part C: Brenda Bledsoe,
Director/Acting Part C Coordinator
Office of Special Education
State Department of Education
Andrew Johnson Tower, 5th Floor
710 James Robertson Parkway
Nashville, TN 37243-0375
(615) 741-3537
(615) 532-9412 (fax)
✉bbledsoe@mail.state.tn.us
http://www.state.tn.us/
education/teishome.htm

619: Janice Bridwell,
Interim 619 Coordinator
Office of Special Education
State Department of Education
Andrew Johnson Tower, 5th Floor
710 James Robertson Parkway
Nashville, TN 37243-0375
(615) 741-2851
(615) 532-9412 (fax)
✉bridwell@mail.state.tn.us

TEXAS

ICC: Scott Wooldridge, ICC Chair
Texas Early Intervention Program
4900 North Lamar
Austin, TX 78751-2399
(512) 424-6754
(512) 424-6749 (fax)
✉barw@airmail.net

Part C: Mary Elder,
Executive Director
Donna Samuelson,
Part C Coordinator
Texas ECI Program
Brown-Heatly State Office Bldg
4900 North Lamar
Austin, TX 78751-2399
(512) 424-6754
(512) 424-6749 (fax)
✉mary.elder@eci.state.tx.us
✉donna.samuelson@eci.state.tx.us
http://www.eci.state.tx.us/

619: Cindy Savage,
619 Coordinator
Texas Education Agency
1701 North Congress Avenue
Austin, TX 78701-1494
(512) 463-9414
(512) 463-9560 (fax)
✉csavage@tmail.tea.state.tx.us
http://www.tea.state.tx.us/

UTAH

ICC: Caroline Bass, ICC Chair
The Learning Center for Families
1192 West Sunset Boulevard, #2
St. George, UT 84770
(435) 673-5353
(435) 673-5393 (fax)
✉cbassot@infowest.com

Part C: Susan Ord,
Part C Coordinator
Baby Watch Early Intervention
State Department of Health
PO Box 144720
Salt Lake City, UT 84114-4720
(801) 584-8441
(801) 584-8496 (fax)
✉sord@doh.state.ut.us
http://hlunix.hl.state.ut.us/cfhs/
cshcn/Bweip/

619: Brenda Broadbent,
619 Coordinator
Special Education Services Unit
State Office of Education
250 East 500 S
Salt Lake City, UT 84111
(801) 538-7708
(801) 538-7991 (fax)
✉bbroadbe@usoe.k12.ut.us
http://www.usoe.k12.ut.us/

VERMONT

ICC: Terrell Walton, ICC Co-Chair
315 Deer Ridge Road
Townshend, VT 05383
(802) 365-4882
✉walton@sover.net

ICC: Marisa Edwards,
ICC Co-Chair
Winston Prouty Center
10 Oak Street
Brattleboro, VT 05301
(802) 257-7852
(802) 258-2413 (fax)
✉wpcme@sover.net

Part C: Helen Keith,
Part C Coordinator
Family, Infant and Toddler Project
PO Box 70
Burlington, VT 05402
(802) 865-1786
(802) 863-7635 (fax)
✉hkeith@vdh.state.vt.us
http://www.state.vt.us/health/
hi/cshn/fitp/fitp.htm

619: Kathy Andrews,
619 Coordinator
Special Education Unit
State Department of Education
120 State Street
Montpelier, VT 05620
(802) 828-5115
(802) 828-3140 (fax)
✉kandrews@doe.state.vt.us

VIRGINIA

ICC: Anne Stewart, ICC Chair
School of Psychology MCC 7401
James Madison University
Harrisonburg, VA 22801
(540) 568-6601
(540) 568-3322 (fax)
✉stewaral@jmu.edu

Part C: Anne Lucas,
Part C Coordinator
Infant and Toddler Program
Dept. of MH/MR/SA Services
PO Box 1797
Richmond, VA 23218
(804) 371-6592
(804) 371-7959 (fax)
✉alucas@dmhmrsas.state.va.us
http://www.dmhmrsas.state.
va.us/vababiescantwait/

619: Linda Bradford,
Principal Specialist
Office of Special Education
State Department of Education
PO Box 2120
Richmond, VA 23218-2120
(804) 225-2675
(804) 371-8796 (fax)
✉lbradfor@mail.vak12ed.edu
http://www.pen.k12.va.us/

VIRGIN ISLANDS

ICC: Michelle LaCoss, ICC Chair
PO Box 1758
St. Croix, VI 00841
(340) 692-2323
(340) 773-6121 (fax)
✉bigmango85@hotmail.net

ICC: Maureen W. Moorehead,
ICC Vice Chair
P. O. Box 5622
St. Croix, VI 00823

Part C: Position Vacant
Mavis Mattnew,
Acting Comissioner
Department of Health
PO Box 9965
St. Thomas, VI 00801

619: Belinda O'Neal, Acting
Special Education Director
Division of Special Education
Department of Education
#44-46 Kongens Gaden
Charlotte Amalie
St. Thomas, VI 00802
(340) 776-5802
(340) 774-0817 (fax)
✉bwoneal@usviosep.org

WASHINGTON

ICC: Jean Kelly, ICC Chair
University of
Washington/CHDD/SB212
Box 357920
Seattle, WA 98195-7920
(206) 685-3387
(206) 543-9266 (fax)
✉jkelly@U.Washington.edu

Part C: Sandy Loerch,
Part C Coordinator
Infant Toddler Early
Interv. Program
Department of Social
and Health Services
12th and Franklin Streets
PO Box 45201
Olympia, WA 98504-5201
(360) 902-8490
(360) 902-8497 (fax)
✉loercsk@dshs.wa.gov
http://www.wa.gov/dshs/
iteip/iteip.html

619: Anne Shureen,
619 Coordinator
Office of Superintendent
of Public Instruction
Old Capitol Building, FG-11
600 South Washington Street
PO Box 47200
Olympia, WA 98504
(360) 725-6075
(360) 586-0247 (fax)
✉ashureen@ospi.wednet.edu
http://www.k12.wa.us/

WEST VIRGINIA

ICC: Gail A. Foley,
Acting ICC Chair
Route 1, Box 631
Greenwood, WV 26415
(304) 873-1834
✉gfoley@olinc.net

Part C: Pam Roush,
Part C Coordinator
Early Intervention Program
Office of Maternal
and Child Health
Department of Health
and Human Resources
350 Capital Street, Room 427
Charleston, WV 25301
(304) 558-6311
(304) 558-4984 (fax)
✉pamroush@wvdhhr.org

619: Ginger Huffman,
619 Coordinator
Office of Special Education
Administration
State Department of Education
Capitol Complex, Building 6,
Room 304
1900 Kanawha Boulevard East
Charleston, WV 25305-0330
(304) 558-2696
(304) 558-3741 (fax)
✉huffmanv@aol.com

WISCONSIN

ICC: C. W. King, ICC Chair
P. O. Box 425
Chippewa Falls, WI 54729
(715) 829-8155
✉CWofCFWI@aol.com

Part C: David Sorenson,
Part C Coordinator
Birth to 3 Program
Department of Health
and Family Services
PO Box 7851
1 West Wilson Street, Room 418
Madison, WI 53707-7851
(608) 267-3270
(608) 261-6752 (fax)
✉sorendm@dhfs.state.wi.us
http://www.dhfs.state.wi.us/
bdds/b3.htm

619: Jenny Lange,
Program Supervisor
Bureau for Exceptional Children
Department of Public Instruction
PO Box 7841
Madison, WI 53707
(608) 267-9172
(608) 267-3746 (fax)
✉jeanette.lange@dpi.state.wi.us
http://www.dpi.state.wi.us/dpi/
dltcl/bbfcsp/ecspedhm.html

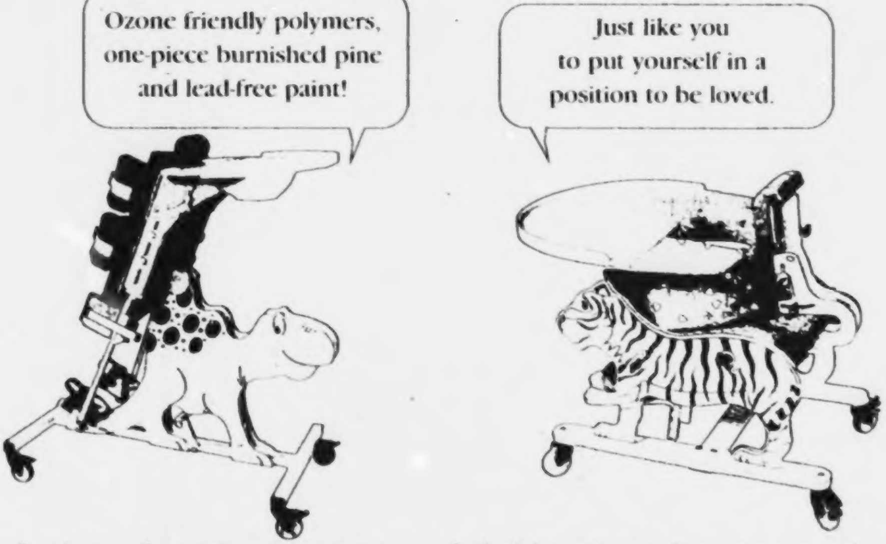
WYOMING

ICC: Donna Merrill, ICC Chair
Director of Stride Learning Center
326 Parsley Boulevard
Cheyenne, WY 82002
(307) 632-2991
(307) 632-6271 (fax)
✉donnamerrill@worldnet.att.net

Part C: Jason Jones,
Part C Coordinator
Wyoming Developmental
Disabilities Division
Herschler Building
122 West 25th Street
Cheyenne, WY 82002
(307) 777-6972
(307) 777-6047 (fax)
✉jjones2@state.wy.us
http://ddd.state.wy.us/
Documents/mitch1.htm

619: Interim Contact TBA
Division of Developmental
Disabilities
1409 First Floor West
Herschler Building
122 West 25th Street
Cheyenne, WY 82002-0050
(307) 777-5246
(307) 777-6047 (fax)

619: Patricia Renton,
619 Coordinator
Department of Education
Special Education Unit
Hathaway Building, 2nd Floor
2300 Capitol Avenue
Cheyenne, WY 82002-0050
(307) 777-3549
(307) 777-6234 (fax)
✉prenton@educ.state.wy.us


Ozone friendly polymers, one-piece burnished pine and lead-free paint!
Just like you to put yourself in a position to be loved.

Introducing a brand new species of children's positioning equipment.
JENX.
The perfect positioning. For body. And soul.
Distributed by BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #32 or visit www.eparent.com/adinfo

103

FEDERAL & FEDERALLY FUNDED INFORMATION RESOURCES

The federal government supports many clearinghouses, information centers, and institutes that focus on specific topics. In addition to publishing and distributing extensive free material on disability-related subjects, many of the clearinghouses, centers, and institutes also provide referrals to local resources. For more information on federal and federally-funded information resources, contact:

- **NICHCY** (National Information Center for Children and Youth with Disabilities), PO Box 1492, Washington, DC 20013-1492; (800) 695-0285 (V/TDD); (202) 884-8200 (V/TDD); (202) 884-8441 (fax).
- **NARIC** (National Rehabilitation Information Center), 1010 Wayne Ave., Ste. 800, Silver Spring, MD 20910; (800) 346-2742; (301) 562-2400; (301) 495-5626 (TDD); (301) 562-2401 (fax).
- **NHIC** (National Health Information Center), PO Box 1133, Washington, DC 20013-1133; (800) 336-4797; (301) 984-4256 (fax).

USING THIS DIRECTORY

When available, World Wide Web sites and e-mail addresses have been included. Web sites include the standard http:// before each address. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ACCESSIBILITY

The Access Board
1331 F St., NW, Ste. #1000
Washington, DC 20004-1111
(202) 272-5434
(202) 272-5449 (TDD)
(202) 272-5447 (fax)
✉info@access-board.gov
http://www.access-board.gov

AIDS

Centers for Disease Control (CDC) National Prevention Information Network
PO Box 6003
Rockville, MD 20849-6003
(800) 458-5231
(800) 243-7012 (TDD)
(888) 282-7681 (fax)
(301) 562-1098 (international line)
(301) 588-1589 (international TDD)
(301) 562-1058 (international fax)
✉info@cdcnpin.org
http://www.cdcnpin.org

CDC National STD and AIDS Hotlines
(800) 227-8922
(800) 342-2437 (English)
(800) 344-7432 (Spanish)
(800) 243-7889 (TDD)
http://www.sashastd.org
http://www.iwannaknow.org

ALLERGY & INFECTIOUS DISEASES

National Institute of Allergy & Infectious Diseases
Office of Communication and Public Liaison
31 Center Dr., MSC 2520
Bldg. 31, Rm. 7A-50
Bethesda, MD 20892-2520
(301) 496-5717
(301) 402-0120 (fax)
✉ocpostoffice@niaid.nih.gov
http://www.niaid.nih.gov

ARTS

National Arts and Disability Center
300 UCLA Medical Plaza, Ste. 3310
Los Angeles, CA 90095-6967
(310) 794-1141
(310) 794-1143 (fax)
✉oraynor@mednet.ucla.edu
http://nadc.ucla.edu

ASSISTIVE TECHNOLOGY & REHABILITATION EQUIPMENT

ABLEDATA
8630 Fenton St., Ste. 930
Silver Spring, MD 20910
(800) 227-0216
(301) 608-8998
(301) 608-8912 (TDD)
(301) 608-8958 (fax)
✉abledata@macroint.com
http://www.abledata.com

CANCER

Cancer Information Service National Cancer Institute
NIH Dept. of Health
and Human Services
6116 Executive Blvd.
Room 3036A
Bethesda, MD 20892-8322
(800) 422-6237
(800) 332-8615 (TDD)
(301) 402-2594 (fax)
http://www.nci.nih.gov

DIABETES

National Diabetes Information Clearinghouse
1 Information Way
Bethesda, MD 20892-3560
(301) 654-3327
(301) 907-8906 (fax)
✉ndic@info.niddk.nih.gov
http://www.niddk.nih.gov

DIGESTIVE DISEASES

National Digestive Diseases Information Clearinghouse
2 Information Way
Bethesda, MD 20892-3570
(800) 891-5389
(301) 654-3810
(301) 907-8906 (fax)
✉nddic@info.niddk.nih.gov
http://www.niddk.nih.gov

DISABILITIES

NICHCY (National Information Center for Children & Youth with Disabilities)
PO Box 1492
Washington, DC 20013-1492
(800) 695-0285 (voice/TDD)
(202) 884-8200 (voice/TDD)
(202) 884-8441 (fax)
✉nichcy@aed.org
http://www.nichcy.org

EDUCATION

ERIC Clearinghouse on Disabilities & Gifted Children
Council for Exceptional Children
1110 N. Glebe Rd.
Arlington, VA 22201
(800) 328-0272 (voice/TDD)
✉ericec@cec.sped.org
http://ericec.org

(NAEYC) National Association for the Education of Young Children
1509 16th St. NW
Washington, DC 20036-1426
(800) 424-2460
(202) 232-8777
(202) 328-1846 (fax)
✉pubaff@aeyc.org
http://www.naeyc.org

American Council on Education
HEATH Resource Center
1 Dupont Circle NW, Ste. 800
Washington, DC 20036-1193
(800) 544-3284 (voice/TDD)
(202) 939-9300 (voice/TDD)
(202) 833-4760 (fax)
✉heath@ace.nche.edu
http://www.heath-resource-center.org

Federal Resource Center for Special Education
Academy for Educational Development
1825 Connecticut Ave., NW
Washington, DC 20009
(202) 884-8215
(202) 884-8200 (TDD)
(202) 884-8443 (fax)
✉frc@acd.org
http://www.dssc.org/frc

Office of Special Education & Rehabilitation Services
US Department of Education
330 C St., SW
Switzer Bldg., Rm. 3132
Washington, DC 20202-2524
(202) 205-8241
(202) 205-4208 (TDD)
(202) 401-2608 (fax)
http://www.ed.gov/offices/osers

EMPLOYMENT

Job Accommodation Network
West Virginia University
PO Box 6080
Morgantown, WV 26506-6080
(800) 232-9675 (voice/TDD)
(800) 526-7234 (voice/TDD)
(304) 293-5407 (fax)
✉jan@jan.icdi.wva.edu
http://www.jan.wuv.edu

Office of Disability Employment Policy - US Dept. of Labor
1331 F St. NW, 3rd Fl.
Washington, DC 20004
(202) 376-6200
(202) 376-6205 (TDD)
(202) 376-6219 (fax)
http://www.dol.gov/dol/odep

FAMILY HEALTH

Agency for Health Care Research and Quality
Publications Clearinghouse
PO Box 8547
Silver Spring, MD 20907-8547
(800) 358-9295
(301) 594-2800 (fax)
http://www.ahrq.gov

National Center for Education in Maternal & Child Health
2000 15th St. N., Ste. 701
Arlington, VA 22201-2617
(703) 524-7802
(703) 524-9335 (fax)
✉info@ncemch.org
http://www.ncemch.org

National Center for Health Statistics
6525 Belcrest Rd.
Hyattsville, MD 20782-2003
(301) 458-4636
http://www.centers for disease control (cdc).gov/nchs

HSC Health Care System
1025 Connecticut Ave.
Washington, DC 20036
(800) 329-6884
(202) 467-2737
(202) 467-2737 (fax)
✉hscsn@hscsn.org
http://www.hscsn.org

National Health Information Center (NHIC)
PO Box 1133
Washington, DC 20013-1133
(800) 336-4797
(301) 567-4167 (Maryland only)
(301) 984-4256 (fax)
✉info@nhic.org
http://www.healthfinder.gov

National Institute of Child Health & Human Development
NICHD Clearinghouse
PO Box 3006
Rockville, MD 20847
(800) 370-2943
(301) 984-1473 (fax)
✉NICHDclearinghouse@mail.nih.gov
http://www.nichd.nih.gov

National Institutes of Health (NIH)
Office of Rare Diseases
31 Center Dr., MSC 2084
Bldg. 31, Rm. 1B-19
Bethesda, MD 20892
(301) 402-4336
(301) 480-9665 (fax)
✉hh707@nih.gov
http://rarediseases.info.nih.gov/ord

National Maternal & Child Health Clearinghouse
2070 Chain Bridge Rd., Ste. 450
Vienna, VA 22182
(888) 434-4624
(703) 821-8955
(703) 556-4831 (TDD)
(703) 821-2098 (fax)
✉nmchc@circsol.com
http://www.circsol.com

HEARING IMPAIRMENTS

National Deaf Education Network and Clearinghouse
KDES PAS-6
800 Florida Ave. NE
Washington, DC 20002-3695
(202) 651-5051
(202) 651-5052 (TDD)
(202) 651-5044 (fax)
✉Clearinghouse.infotogo@gallaudet.edu
http://clerccenter.gallaudet.edu

National Institute on Deafness & Other Communication Disorders
Information Clearinghouse
1 Communication Ave.
Bethesda, MD 20892-3456
(800) 241-1044
(800) 241-1055 (TDD)
(301) 907-8830 (fax)
✉nidcdinfo@nidcd.nih.gov
http://www.nidcd.nih.gov

HEART, LUNG, AND BLOOD DISORDERS

National Heart, Lung, & Blood Institute Information Center
PO Box 30105
Bethesda, MD 20824-0105
(301) 592-8573
(301) 592-8563 (fax)
✉nhlbinfo@rover.nhlbi.gov
http://www.nhlbi.nih.gov

HOUSING

Housing & Urban Development
PO Box 6091
Rockville, MD 20849
(800) 245-2691
(800) 483-2209 (TDD)
(301) 519-5767 (fax)
✉huduser@aspensys.com
http://www.huduser.org

KIDNEY AND UROLOGIC DISEASES

National Kidney & Urologic Diseases Information Clearinghouse
3 Information Way
Bethesda, MD 20892-3580
(301) 654-4415
(800) 891-5390
(301) 907-8906 (fax)
✉nkudic@info.niddk.nih.gov
http://www.niddk.nih.gov

MENTAL HEALTH

(KEN) National Mental Health Services Knowledge Exchange Network
PO Box 42490
Washington, DC 20015
(800) 789-2647
(301) 984-8796 (fax)
✉ken@mentalhealth.org
http://www.mentalhealth.org

Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute
Portland State University
PO Box 751
Portland, OR 97207
(503) 725-4040
(503) 725-4180 (fax)
http://www.rtc.pdx.edu

MUSCULOSKELETAL & SKIN DISEASES

National Arthritis & Musculoskeletal & Skin Diseases Information Clearinghouse
1 AMS Cir.
Bethesda, MD 20892-3675
(877)226-4267
(301) 495-4484
(301) 565-2966 (TDD)
(301) 718-6366 (fax)
✉namsic@mail.nih.gov
http://www.nih.gov/niams

NEUROLOGICAL DISORDERS

National Institute of Neurological Disorders & Stroke
PO Box 5801
Bethesda, MD 20824
(800) 352-9424
(301) 496-5751
(301) 402-2186 (fax)
http://www.ninds.nih.gov

ORAL HEALTH

National Oral Health Information Clearinghouse
1 NOHIC Way
Bethesda, MD 20892-3500
(301) 402-7364
(301) 656-7581 (TDD)
(301) 907-8830 (fax)
✉nohic@nider.nih.gov
http://www.nohic.nider.nih.gov

PRIMARY CARE

National Clearinghouse for Primary Care Information
Circle Solution Inc.
2070 Chain Bridge Rd., Ste. 450
Vienna, VA 22182
(800) 400-2742
(703) 566-4831 (TDD)
(703) 821-2098 (fax)
✉primarycare@circsol.com
http://www.bahc.hosa.gov/ncpci/publist

REHABILITATION

NARIC (National Rehabilitation Information Center)
1010 Wayne Ave., Ste. 800
Silver Spring, MD 20910-3319
(800) 346-2742
(301) 495-5626 (voice/TDD)
(301) 562-2401 (fax)
✉naricinfo@kra.com
http://www.naric.com

TRANSITIONING

National Transition Alliance for Youth with Disabilities (NTA)
Transition Research Institute at Illinois
117 Children's Research Center
51 Gerty Dr.
Champaign, IL 61820
(217) 333-2325 (voice/TDD)
(217) 244-0851 (fax)
✉nta@aed.org
http://www.ed.uiuc.edu/sped/tri/institute.html

VISUAL IMPAIRMENTS

National Eye Institute
31 Center Dr., MSC 2510
Bldg. 31, Rm. 6A-32
Bethesda, MD 20892-2510
(301) 496-5248
(301) 402-1065 (fax)
✉2020@nei.nih.gov
http://www.nei.nih.gov

OTHER FEDERAL RESOURCES

These federal resources can provide information on programs, services, and related laws and regulations.

Dept. of Health & Human Services
Admin. For Children and Families
Admin. on Developmental Disabilities (ADD)
370 L'Enfant Promenade, SW
Room 300F
Washington, DC 20447
(202) 690-6590
(202) 690-6904 (fax)
http://www.acf.dhhs.gov/programs/add/

Department of the Interior National Park Service
1849 C St. NW
Washington, DC 20240
(202) 208-4747
(202) 219-0910 (fax)
http://www.nps.gov

National Center on Birth Defects and Developmental Disabilities
4770 Buford Hwy., NE
Mailstop F-15
Atlanta, GA 30341
(770) 488-7400
(770) 488-7361 (fax)
http://www.centers for disease control (cdc).gov/ncbddd

National Council on Disability
1331 F St. NW, Ste. 1050
Washington, DC 20004-1107
(202) 272-2004
(202) 272-2074 (TDD)
(202) 270-2022 (fax)
http://www.ncd.gov

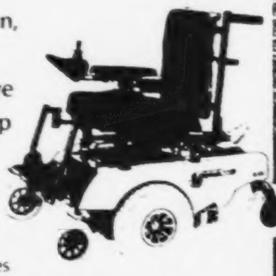
National Library Service for the Blind & Physically Handicapped
Library of Congress
Reference Sec.
1291 Taylor St. NW
Washington, DC 20542
(202) 707-5100
(202) 707-0744 (TDD)
(202) 7070-0712 (fax)
✉nls@loc.gov
http://www.loc.gov/nls

Office for Disability Issues Human Resources Development, National Clearinghouse, Canada
25 Eddy St., Ste. 100
Hull, PQ K1A 0M5
(800) 665-9017 (Canada only)
(800) 561-9706 (TDD Canada only)
(819) 994-7514
(819) 953-4797 (fax)
✉odi@indie.ca
http://www.indie.ca/odihrdc-orhc.gc.ca

Office for Fair Housing & Equal Opportunity Department of Housing & Urban Development
Washington, DC 20002
(202) 275-0848
(202) 275-0772 (TDD)
(202) 275-2987 (fax)
http://www.hud.gov

President's Committee on Mental Retardation
370 L'Enfant
Promenade SW
Ste. 701
Washington, DC 20447
(202) 619-0634
(202) 205-9519 (fax)

Social Security Administration
6401 Security Blvd.
Baltimore, MD 21235
(800) 772-1213
(800) 325-0778 (TDD)
http://www.ssa.gov



QUANTUM™
DYNAMO®

The Quantum™ Dynamo® series offers children fun, independence and confidence in their abilities. With Quantum Rehab's patented mid-wheel drive performance, children can play, explore and keep up with their friends.

- Kid-friendly styling and six all-new fun colors that allow children to express their own individuality
- Compact size delivers easy turning, even in kid-sized spaces
- Achieves sizes as small as 10" x 10" with Versa Seat and 12" x 12" with power tilt
- Seat-to-floor heights as low as 15" - perfect for maneuvering under school desks
- Available dual platforms provide easier transfer and extra support for shorter legs
- On-board battery charger for added convenience
- Disassembles for easy transport

QUANTUM
LEAPING AHEAD WITH MORE ADVANCED REHAB PRODUCTS AND SERVICES

(U.S.) 1-866-800-2002 • (Canada) 1-888-570-1113
www.quantumrehab.com

Circle #108 or visit www.eparent.com/adinfo

NATIONAL INFORMATION & ADVOCACY RESOURCES

These national organizations are information and advocacy resources for families and professionals. Many of these organizations provide a variety of services, others focus on more specific areas of concern. Numbers following each listing correspond to items listed in the **Key to Services,** which describes services provided by individual organizations. We have tried to list as much information as possible on each group, but it is best to contact the organization directly for a full description of services.

When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the symbol, ✉. Web sites are listed with the standard http:// before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

ACCESSIBLE PLAYGROUNDS

Boundless Playgrounds Inc.
One Regency Dr.
Bloomfield, CT 06002-2310
(877) 268-6353
(860) 243-8315
(860) 243-5854 (fax)
✉info@boundlessplaygrounds.org
http://www.boundlessplaygrounds.org
1,2,3,4,7,9; *helping communities develop accessible playgrounds*

ADOPTION

A Kids Exchange
c/o Janet Marchese
56 Midchester Ave.
White Plains, NY 10606
(914) 428-1236
3

AASK: Adopt A Special Kid
7700 Edgewater Dr., Ste. 125
Oakland, CA 94621
(888) 680-7349
(510) 553-1748
(510) 553-1747 (fax)
✉andrea@adoptaspecialkid.org
http://www.adoptaspecialkid.org
1,2,3,5

Adoptive Families
42 West 38th St.,Suite 901
New York, NY, 10018
(800) 372-3300
(646) 366-0830
http://www.AdoptiveFamilies-Magazine.com
1,2,4

Jewish Children's Adoption Network
PO Box 147016
Denver, CO 80214-7016
(303) 573-8113
(303) 893-1447 (fax)
✉jcan@Qswest.net
http://www.users.qwest.net/~jcan
1,2,3,4,5,6,9;
Hebrew/Yiddish materials

National Adoption Center
1500 Walnut St., Ste. 701
Philadelphia, PA 19102
(800) 862-3678
(215) 735-9988
(215) 735-9410 (fax)
✉nac@adopt.org
http://www.adopt.org
1,2,3,5

Spaulding for Children
16250 Northland Dr., Ste. 120
Southfield, MI 48075
(248) 443-7080
(248) 443-7099 (fax)
✉sfc@spaulding.org
http://www.spaulding.org
1,2,3,6

ARCHITECTURAL ACCESSIBILITY

Center for Universal Design
North Carolina State University
School of Design, Box 8613
219 Oberlin Rd.
Raleigh, NC 27695-8613
(800) 647-6777
(voice/TDD, US & Canada)
(919) 515-3082 (voice/TDD)
(919) 515-3023 (fax)
✉cud@ncsu.edu
http://www.design.ncsu.edu/cud
1,2,4

ARTS

National Arts and Disability Center
300 UCLA Medical Plaza,
Ste. 3310
Los Angeles, CA 90095-6967
(310) 794-1141
(310) 367-2356 (TDD)
(310) 794-1143 (fax)
✉oraynor@mednet.ucla.edu
http://nadc.ucla.edu
2,4,5

ASSISTIVE TECHNOLOGY

Center For Best Practices in Early Childhood Education
27 Horrabin Hall
Western Illinois University
Macomb, IL 61455
(309) 298-1634
(309) 298-2305 (fax)
✉TL_Carley@wiu.edu
http://www.wiu.edu/users/mimacp/wiu
1,2

New Hampshire Assistive Technology Center
67 Communication Drive
Laconia, NH 03246-0109
(603) 528-3060
(603) 524-0702 (fax)
✉nhatech@cyberportal.net
1,2,4

Lekotek's CompuPlay Programs
The National Lekotek Center
2100 Ridge Ave.
Evanston, IL 60201
(800) 366-7529 (Toy Resource Helpline)
(847) 328-0001
(800) 573-4446 (TDD)
(847) 328-5514 (fax)
✉lekotek@lekotek.org
http://www.lekotek.org
1,2,3,4,5

BEREAVEMENT SUPPORT

Center for Loss in Multiple Birth (CLIMB), Inc.
c/o Jean Kollantai
PO Box 91377
Anchorage, AK 99509
(907) 222-5321
(907) 222-5321 (fax)
✉climb@pobox.alaska.net
http://www.climb-support.org
1,2,3,4,7; *Support provided by and for parents who have experienced the death of one or more, both or all twins or higher multiples, conception through childhood—US & Canada*

The Compassionate Friends, Inc.
PO Box 3696
Oak Brook, IL 60522-3696
(877) 969-0010
(630) 990-0010
(630) 990-0246 (fax)
✉nationaloffice@compassionate-friends.org
http://www.compassionate-friends.org
1,2,5,6;
Support to families grieving the death of a child regardless of age or cause. Spanish materials

Pen-Parents
PO Box 8738
Reno, NV 89507-8738
(702) 826-7332
(702) 826-0632 (fax)
✉PenParents@prodigy.com
http://www.pages.prodigy.com/nv/fgck08a/penparents.html
1,2,3,4

Pregnancy and Infant Loss Center
1421 E. Wayzata Blvd., #70
Wayzata, MN 55391
(952) 473-9372
(952) 473-8978 (fax)
http://www.pilc.org
1,2,3,4,6,7,
Spanish materials

BREASTFEEDING

La Leche League International
1400 N. Meacham Rd.
Schaumburg, IL 60173
(800) LALECHE (525-3243)
(847) 519-7730
(847) 519-0035 (fax)
✉PRDepartment@llli.org
http://www.lalecheleague.org
1,2,3,4,5,6

CHILD CARE

Child Care Plus+ The Center on Inclusion in Early Childhood
634 Eddy Ave.
The University of Montana
Missoula, MT 59812-6696
(800) 235-4122
(406) 243-5467 (voice/TDD)
(406) 243-4730 (fax)
✉kevind@selway.umt.edu
http://www.ccplus.org
1,2

The Canadian Special Link National Center for Child Care Inclusion
PO Box 775
Sydney, NS CAN B1P 6G9
(800) 840-5465 (Canada only)
(902) 562-1662
(902) 539-9117 (fax)
✉specialink@us-sympatico.ca
http://www.specialinkcanada.org
1,2,7,9

DEVELOPMENTAL DISABILITIES

AAC-RERC on Communication Enhancement
PO Box 3888
Duke University Medical Center
Durham, NC 27710
(919) 681-9983
(919) 681-9984 (fax)
✉kevin.caves@duke.edu
http://www.aac-rerc.com
2,6

Developmental Delay Registry
440 Eastwest Hwy, Ste., 207
Bethesda, MD 20814
(301) 652-2263
(301) 652-9133 (fax)
✉devdelay@mindspring.com
http://www.devdelay.org
1,2,3,5,9

EARLY INTERVENTION

Pathways Awareness Foundation
123 N. Wacker Dr., Ste. 900
Chicago, IL 60606
(800) 955-2445
(847) 729-1116
✉friends@pathwaysawareness.org
http://www.pathways-awareness.org
2,4,7

EDUCATION

National Coalition of Title I/Chapter I Parents
3609 Georgia Ave. NW, 1st Fl.
Washington, DC 20010
(202) 291-8100
(202) 291-8200 (fax)
1,2,4,5,6,7;
scholarship program

EMPLOYMENT

Electronic Industries Foundation
2500 Wilson Blvd., Ste. 210
Arlington, VA 22201
(703) 907-7400
(703) 907-7422 (TDD)
(703) 907-7401 (fax)
http://www.eiafoundation.org
Scholarship program

Job Opportunities for the Blind
National Federation of the Blind
1800 Johnson St.
Baltimore, MD 21230
(410) 659-9314
(410) 685-5653 (fax)
✉nfb@nfb.org
http://www.nfb.org
1,2,3,4,5,6,7

Just One Break, Inc.
120 Wall St., 20th Fl.
New York, NY 10005
(212) 785-7300
(212) 785-4513 (fax)
✉justonebreak@interactive.net
✉jobs@justonebreak.com
http://www.justonebreak.com
1,2,5,6;
information in braille

Mainstream
6930 Carroll Ave., Ste. 240
Takoma Park, MD 20912
(301) 891-8777 (voice/TDD)
(301) 891-8778 (fax)
✉info@mainstreaminc.org
http://www.mainstreaminc.org
1,2,4

National Industries for the Severely Handicapped
2235 Cedar Ln.
Vienna, VA 22182
(703) 560-6800
(703) 849-8916 (fax)
✉info@nish.org
http://www.nish.org
1,2,5,6,7

Parents Alliance Employment Project
Illinois Employment
& Training Center
837 S. Westmore Rd.
Lombard, IL 60148
(630) 495-4345 ext. 211
(630) 495-6055 (TDD)
(630) 495-0387 (fax)
✉tweekley@etc-dupageco.com
1,2,3,4

GENERAL

Advocates Across America
PO Box 754
Chandler, AZ 85244-0754
(480) 917-0955
(480) 814-9404 (fax)
✉support@axa.org
http://www.axa.org
1,2,3,4

The American Association of Retired Persons (AARP)
601 E St. NW
Washington, DC 20049
(800) 424-3410
(202) 434-6561
✉eads@aarp.org
http://www.aarp.org

Association of University Centers On Disabilities
8630 Fenton St., Ste. 410
Silver Spring, MD 20910
(301) 588-8252
(301) 588-3319 (TDD)
(301) 588-2842 (fax)
http://www.aucd.org
2,4,6,7

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

The Arc of the U.S.
1010 Wayne Ave., Ste. 650
Silver Spring MD, 20710
(301) 565-3842
(301) 565-5342 (fax)
✉info@thearc.org
http://www.TheArc.org
1,4

Birth Defect Research for Children
930 Woodcock Rd., Ste. 225
Orlando, FL 32803
(407) 895-0802
(407) 895-0824 (fax)
http://www.birthdefects.org
1,2,3,4,7,9

Children's Defense Fund
25 E St. NW
Washington, DC 20001
(800) 233-1200
(202) 628-8787
(202) 662-3510 (fax)
✉cdfinfo@childrensdefense.org
http://www.childrensdefense.org
2,6,7

Council for Exceptional Children
1110 Glebe Rd., Ste. 300
Arlington, VA 20191-1589
(888) 232-7733
(703) 264-9494 (fax)
✉service@cec.sped.org
http://www.cec.sped.org
1,2,5,6,7

Easter Seals
230 W. Monroe, Ste. 1800
Chicago, IL 60606-4802
(800) 221-6827
(312) 726-6200
(312) 726-4258 (TDD)
(312) 726-1494 (fax)
✉info@easter-seal.org
http://www.easter-seal.org
2,4,5;
Easter Seals provides a wide variety of services including early intervention, job training/assistance, rehabilitation, respite, and more.

Family Voices
3411 Candelaria NE, Ste. M
Albuquerque, NM 87107
(888) 835-5669
(505) 872-4774
(505) 872-4780 (fax)
✉kidshealth@familyvoices.org
http://www.familyvoices.org
1,2,5,6

KDWB Variety Family Center
University of Minnesota Gateway
200 Oak St. SE, Ste. 160
Minneapolis, MN 55455-2002
(612) 626-3087
(612) 624-0997
✉kdwb-var@umn.edu
http://www.peds.umn.edu/peds-adol/
1,2,4,7
Family resource center; also provides clinical services.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave.
White Plains, NY 10605
(888) MODIMES (663-4637)
(914) 428-8203 (fax)
✉resourcecenter@modimes.org
http://www.modimes.org
2,5,7,8; *Information on several thousand birth defects and genetic conditions.*

National Family Caregivers Association
10400 Connecticut Ave., Ste. 500
Kensington, MD 20895-3944
(800) 896-3650
(301) 942-6430
(301) 942-2302 (fax)
✉info@nfcacares.org
http://www.nfcacares.org
1,2,4,7

Washington State National Father's Network
The Kindering Center
16120 NE 8th St.
Bellevue, WA 98008-3937
(425) 747-4004 ext. 218
(206) 284-2859
(425) 747-1069 (fax)
(206) 284-9664 (fax)
✉jmay@fathersnetwork.org
http://www.fathersnetwork.org
1,2,3,4,5,6,7

National Vaccine Network
421-E Church St.
Vienna, VA 22180
(703) 938-0342
(703) 938-5768 (fax)
✉info@909shot.com
http://www.909shot.com
1,2,3,4 (regional conferences), 5,6,7,9

NICHCY: National Information Center for Children and Youth with Disabilities
PO Box 1492
Washington, DC 20013-1492
(800) 695-0285 (voice/TDD)
(202) 884-8200 (voice/TDD)
(202) 884-8441 (fax)
✉nichcy@aed.org
http://www.nichcy.org
2,4;
many publications available in Spanish

NPA: National Perinatal Association
3500 E. Fletcher Ave., Ste. 205
Tampa, FL 33613-4712
(888) 971-3295
(813) 971-1008
(813) 971-9306 (fax)
✉npa@nationalperinatal.org
http://www.nationalperinatal.org
1,2,3,5,6

NPND: National Parent Network on Disabilities
1130 17th St., NW, Ste. 400
Washington, DC 20005
(202) 463-2299
(202) 463-9405 (fax)
✉npnd@mindspring.com
http://www.npnd.org
1,2,4,5,6,7

RESNA
1700 N. Moore St., Ste. 1540
Arlington, VA 22209-1903
(703) 524-6686
(703) 524-6639 (TDD)
(703) 524-6630 (fax)
✉info@resna.org
http://www.resna.org

The Roeher Institute
Kinsmen Bldg., York University
4700 Keele St.
North York, ON CAN M3J IP3
(416) 661-9611
(416) 661-5701 (fax)
✉info@roeher.ca
1,2,5,6,7

SNAP: Special Needs Advocate for Parents
1801 Avenue of the Stars, #401
Century City, CA 90067
(888) 310-9889
(310) 201-9614
(310) 201-9889 (fax)
✉info@snapinfo.org
http://www.snapinfo.org
1,2,4,5,6,

STOMP: Specialized Training of Military Parents
c/o Washington PAVE
6316 S. 12th St.
Tacoma, WA 98465-1900
(800) 5-PARENT (voice/TDD)
(253) 565-2266 (voice/TDD)
(253) 566-8052 (fax)
✉hhebdon@washingtonpave.com
http://www.washingtonpave.org

The University of Montana Rural Institute: A Center for Excellence in Developmental Disabilites, Research, Education, and Service
52 Corbin Hall
Missoula, MT 59812-7056
(800) 732-0323
(406) 243-5467 (voice/TDD)
(406) 243-4730 (fax)
✉muarid@selway.umt.edu
http://www.ruralinstitute.umt.edu
1,2,4,6,7

World Institute on Disability
510 16th St., Ste. 100
Oakland, CA 94612-1502
(510) 763-4100
(510) 208-9496 (TDD)
(510) 763-4109 (fax)
✉webpoobah@wid.org
http://www.wid.org
2,4

GENETICS

BridgeMar Research Foundation
PO Box 341
Crete, IL 60417
(708) 672-7599
✉bridgemar1@aol.com
http://www.bridgemar.org
3,8
Funds research into unknown genetic diseases in children.

Genctic Alliance
4301 Connecticut Ave. NW, Ste. 404
Washington, DC 20008-2304
(800) 336-GENE (Helpline)
(202) 966-5557
(202) 966-8553 (fax)
✉info@geneticalliance.org
http://www.geneticalliance.org
2,4,6

Hereditary Disease Foundation
11400 W. Olympic Blvd., Ste. 855
Los Angeles, CA 90064
(310) 575-9656
(310) 575-9156 (fax)
✉cures@hdfoundation.org
http://www.hdfoundation.org
1,8

HEALTHCARE

National Health Council
1730 M St. NW, Ste. 500
Washington, DC 20036-4505
(202) 785-3910
(202) 785-5923 (fax)
✉info@nationalhealthcouncil.org
http://www.nationalhealthcouncil.org
1,2,4,6,7

St. Mary's Healthcare System for Children
c/o Rhonda Broden
29-01 216th St
Bayside, NY 11360
(718) 281-8800
(718) 281-7874(fax)
✉info@stmaryskids.org
http://www.stmaryskids.org
5,6,7

HOSPITALITY HOUSING/HOSPICE

Childrens Hospice International
901 North Pitt St. Suite 230
Alexandria, VA 22314
(800) 24-CHILD (242-4453)
(703) 684-0330
(703) 684-0226 (fax)
✉chiorg@aol.com
http://www.chionline.org
2,3,4,6,7

Hospitality Program
138 Tremont St.
Boston, MA 02111
(617) 482-4338
(617) 482-8431 (fax)
✉info@hosp.org
http://www.hosp.org
Boston area

National Association of Hospital Hospitality Houses
PO Box 18087
Asheville, NC 28814-0087
(800) 542-9730
(828) 253-1188
(828) 253-8082 (fax)
✉helpinghomes@nahhh.org
http://www.nahhh.org
1,2,4,6,9.

INDEPENDENT LIVING

Disabled and Alone/Life Services for the Handicapped, Inc.
352 Park Ave. S.,11th Floor
New York, NY 10010-1709
(800) 995-0066
(212) 532-6740 (voice/fax)
✉disabledandalone@aol.com
http://www.disabledandalone.org
1,2,3,4

Independent Living Research Utilization Program
2323 S. Shepherd, Ste. 1000
Houston, TX 77019
(713) 520-0232
(713) 520-5136 (TDD)
(713) 520-5785 (fax)
✉ilru@ilru.org
http://www.ilru.org
1,2,3,6,7

INFORMATION AND REFERRALS

Brave Kids
1592 Union Street
San Francisco, CA 94123
(415) 561-2393
(415) 561-2397 (fax)
✉info@bravekids.org
http://www.bravekids.org
1,2,3,4,5
Bravekids.org Web site is an online community and resource center for children with chronic, life threatening illnesses and disabilities. The Brave Kids organization also provides computers and webTV's to disadvantaged children who are seriously ill and resource centers to pediatric wards of hospitals.

National Christian Resource Center
Bethesda Lutheran Homes
700 Hoffman Dr.
Watertown, WI 53094
(800) 369-4636 (Info) ext. 418
2,4
Referrals to local services, advocacy and support groups, and religious education programs; Lists of religious materials.

LEGAL ASSISTANCE

DREDF: Disability Rights Education and Defense Fund
Main Office:
2212 Sixth St.
Berkeley, CA 94710
(800) 466-4232 ADA Technical Information Hotline.(voice/TDD)
(510) 644-2555 (voice/TDD)
(510) 841-8645 (fax)
✉dredf@dredf.org
http://www.dredf.org
1,2,3

National Association of Protection and Advocacy Systems
900 2nd St. NE, Ste. 211
Washington, DC 20002
(202) 408-9514
(202) 408-9521 (TDD)
(202) 408-9520 (fax)
✉NAPAS@earthlink.net
http://www.protectionandadvocacy.com
1,2,4,5,6

Pike Institute on Law and Disability
Boston University School of Law
765 Commonwealth Ave.
Boston, MA 02115
(617) 353-2904 (voice/TDD)
(617) 353-2906 (fax)
✉pikeinst@bu.edu
http://www.bu.edu/law/pice
2,4,5

MEDICAL TRAVEL/ TRANSPORTATION

National Patient Travel Center
4620 Haygood Rd., Ste.1
Virginia Beach, VA 23455
(800) 296-1217 (Patient #)
(757) 318-9174 (Administrative #)
(757) 318-9107 (fax)
✉mercymedical@erols.com
http://www.PatientTravel.org

PREMATURITY

The Alexis Foundation for Premature Infants and Children
PO Box 1126
Birmingham, MI 48012-1126
(877) 253-9470
(248) 543-4169 (phone/fax)
✉thealexisfoundation@prodigy.net
http://www.thealexisfoundation.org
1,2,3,4
Also provides preemie clothing.

RARE DISORDERS

Canadian Organization for Rare Disorders
PO Box 814
Coaldale, AB CAN T1M 1M7
(877) 302-7273
(403) 345-4544
(403) 345-3948 (fax)
✉office@cord.ca
http://www.cord.ca
3,5,6

NATIONAL INFORMATION & ADVOCACY RESOURCES

MUMS: National Parent to Parent Network
c/o Julie Gordon
150 Custer Ct.
Green Bay, WI 54301-1243
(920) 336-5333
(877)-336-5333
(920) 339-0995 (fax)
✉mums@netnet.net
http://www.netnet.net/mums/
1,2,3,4,5.

NORD: National Organization for Rare Disorders, Inc.
100 Rt. 37
PO Box 8923
New Fairfield, CT 06812
(800) 999-6673 (voice message)
(203) 746-6518
(203) 746-6927 (TDD)
(203) 746-6481 (fax)
✉orphan@rarediseaseses.org
http://www.rarediseases.org
1,2,3,4,6,7,8

REHABILITATION

Easter Seals/March of Dimes National Council
90 Eglinton Ave. E, Ste. 511
Toronto, ON CAN M4P 2Y3
(416) 932-8382
(416) 932-8151 (TDD)
(416) 932-9844 (fax)
✉national.council@esmodnc.org
http://www.esmodnc.org
4,5,7

Easter Seals
230 W. Monroe, Ste. 1800
Chicago, IL 60606-4802
(800) 221-6827
(312) 726-6200
(312) 726-4258 (TDD)
(312) 726-1494 (fax)
✉info@easter-seal.org
http://www.easter-seal.org

RESPITE CARE

National Respite Locator Service
800 Eastowne Dr., Ste. 105
Chapel Hill, NC 27514
(800) 773-5433
(919) 490-4905 (fax)
http://www.chtop.com/locator.htm
Database with respite services.

SELF-HELP

American Self-Help Group Clearinghouse
100 Hanover Ave., 2nd Fl.
Cedar Knolls, NJ 07927-2020
(973) 326-6789
(973) 326-9467 (fax)
✉ashc@cybernex.net
http://www.selfhelpgroups.org
2,4
Free consultation on national group development.

National Self-Help Clearinghouse
CUNY Grad School, University Ctr.
365 Fifth Ave., Ste. 3300
New York, NY 10016
(212) 817-1822
(212) 817-2990 (fax)
http://www.selfhelpweb.org
2,4

SEXUALITY

Sexuality Information and Education Council of the U.S.
130 W. 42nd St., Ste. 350
New York, NY 10036-7802
(212) 819-9770
(212) 819-9776 (fax)
✉siecus@siecus.org
http://www.siecus.org
1,2,4,7

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

SIBLING SUPPORT

Sibling Support Project
Children's Hospital and Regional Medical Center
PO Box 5371 CL-09
Seattle, WA 98105-0371
(206) 527-5712
(206) 527-5705 (fax)
✉dmeyer@chmc.org
http://www.chmc.org/departmt/sibsupp
2,9

SUICIDE PREVENTION

American Foundation for Suicide Prevention
120 Wall St., 22nd Fl.
New York, NY 10005
(212) 363-3500
(212) 363-6237 (fax)
✉inquiry@afsp.org
http://www.afsp.org
1,2,4,5,6,7,8

SUPPORT

Friends' Health Connection
PO Box 114
New Brunswick, NJ 08903
(800) 483-7436
(732) 418-1811
(732) 249-9897 (fax)
✉info@friendshealthconnection.org
http:/www.friendshealthconnection.org
1,2,3,4

TOY LENDING AND ADAPTATIONS

The National Lekotek Center
2100 Ridge Ave.
Evanston, IL 60201
(800) 366-7529
(Toy Resource Helpline)
(800) 573-4446 (TDD)
(847) 328-5514 (fax)
✉lekotek@lekotek.org
http://www.lekotek.org
1,2,3,4,5

TRAINING PROGRAMS

Project DOCC
Delivery of Chronic Care
One South Rd.
Oyster Bay, NY 11771
(877) 773-8747
(516) 773-8747
(516) 498-1899 (fax)
✉projDOCC@aol.com
http://www.ProjectDOCC.org
1,2,6

TRAVEL

Mobility International USA
PO Box 10767
Eugene, OR 97440
(541) 343-1284 (voice/TTY)
(541) 343-6812 (fax)
✉info@miusa.org
http://www.miusa.org
1,2,3,4 *Educational Travel Exchange*

SATH-The Society for the Advancement of Travel for the Handicapped & Elderly
347 Fifth Ave., Ste. 610
New York, NY 10016
(212) 447-0027
(212) 725-8253 (fax)
http://wwgw.sath.org
1,6

WISH ORGANIZATIONS

Children's Hopes and Dreams
Wish Fulfilment Foundation
280 Rt. 46
Dover, NJ 07801
(973) 361-7366
(973) 361-6627 (fax)
✉chdfdover@juno.com
http://www.childrenswishes.org
1,2,3,4

Children's Wish Foundation International
8615 Roswell Rd.
Atlanta, GA 30350-7526
(800) 323-9474
(770) 393-9474
(770) 393-0683 (fax)
✉wish@childrenswish.org
http://www.childrenswish.org
1,2,4

Grant-A-Wish/The Children's Promise Foundation
c/o Brian Morrison
PO Box 21243
Baltimore, MD 21228
(800) 933-5470
(410) 744-1032
(410) 744-1984 (fax)
✉wish@grant-a-wish.org
http://www.grant-a-wish.org
1,2

Make-A-Wish Foundation of America
3550 N. Central Ave., Ste. 300
Phoenix, AZ 85012
(800) 722- WISH (9474)
(602) 279-WISH (9474)
(602) 279-0855 (fax)
✉mawfa@wish.org
http://www.wish.org
2,4,5

Sunshine Foundation
2001 Bridge St.
Philadelphia, PA 19124
(800) 767-1976
(215) 535-1413
(215) 535-8397 (fax)
2

The Children's Wish Foundation of Canada
95 Bayly St., Ste. 404
Ajax, ON CAN L1S 7K8
(800)700-4437
(905) 426-5656
(905) 426-4111 (fax)
✉lcole@childrenswish.ca
http://childrenswish.ca
1,2,4,5

The Dream Factory
1218 S. Third St.
Louisville, KY 40203
(800) 456-7556
(502) 637-8700
(502) 637-8744 (fax)
✉dfhqtrs@aol.com
http://www.dreamfactoryinc.org
2,4,5

EVALUATION AND EDUCATIONAL PROGRAMMING OF STUDENTS WITH DEAFBLINDNESS AND SEVERE DISABILITIES
Sensorimotor State (2nd Ed.)

Published 2001, 294 pages
Caroll J. Jones
paper ISBN 0-398-07216-7

DEVELOPING AND IMPLEMENTING IDEA-IEPs
An Individualized Education Program (IEP) Handbook for Meeting Individuals with Disabilities Education Act (IDEA) Requirements

Published 2001, 274 pages
Edward Burns
$59.95, hard ISBN 0-398-07122-5
$40.95, paper ISBN 0-398-07123-3

HOW WE SEE GOD AND WHY IT MATTERS
A Multicultural View Through Children's Drawings and Stories

Published 2001, 230 pages
Robert J. Landy
$58.95, hard ISBN 0-398-07170-5
$41.95, paper ISBN 0-398-07171-3

CURRICULUM DEVELOPMENT FOR STUDENTS WITH MILD DISABILITIES
Academic and Social Skills for Inclusion IEPs

Published 2000, 258 pages
Carroll J. Jones
$34.95, spiral (paper) ISBN 0-398-07018-0

AUTISM AND POST-TRAUMATIC STRESS DISORDER
Ending Autistic Fixation

Published 2000, 136 pages
Kenneth Lenchitz
$36.95, cloth ISBN 0-398-07096-2
$19.95, paper (displayed) 0-398-07097-0

Programmed Therapy FOR STUTTERING in Children and Adults (2nd Ed.)

Published 2000, 360 pages
Bruce P. Ryan
$79.95, hard ISBN 0-398-07106-3
$54.95, paper ISBN 0-398-07107-1

MATERNAL NUTRITION AND CHILD HEALTH (2nd Ed.)

Published 2000, 316 pages
Douglas R. Shanklin
$59.95, cloth ISBN 0-398-07074-1
$42.95, paper ISBN 0-398-07075-X

CHILDREN WITH SPECIAL NEEDS
A Resource Guide for Parents, Educators, Social Workers, and Other Care-givers

Published 1999, 234 pages
Karen L. Lungu
$51.95, cloth ISBN 0-398-06933-6
$38.95, paper ISBN 0-398-06934-4 (displayed)

EXCEPTIONAL LEARNERS
Education and Research from a Global Perspective

Published 2001, 260 pages
Ivan Z. Holowinsky
$59.95, cloth ISBN 0-398-07163-2
$38.95, paper ISBN 0-398-07164-0 (displayed)

RESEARCH IN SPECIAL EDUCATION
Designs, Methods, and Applications

Published 2001, 268 pages
Phillip D. Rumrill, Jr., & Bryan G. Cook
$56.95, cloth ISBN 0-398-07172-1
$38.95, paper ISBN 0-398-07173-X (displayed)

EDUCATIONAL INTERVENTIONS AND SERVICES FOR CHILDREN WITH EXCEPTIONALITIES
Strategies and Perspectives (2nd Ed.)
Published 2001, 304 pages
George R. Taylor
$66.95, cloth ISBN 0-398-07112-8
$44.95, paper ISBN 0-398-07113-6 (displayed)

HOME IS WHERE THE ART IS
An Art Therapy Approach to Family Therapy

Published 2001, 224 pages
Doris Banowsky Arrington
$61.95, hard ISBN 0-398-07160-8
$42.95, paper ISBN 0-398-07161-6

SPECIAL EDUCATION, MULTICULTURAL EDUCATION, AND SCHOOL REFORM
Components of Quality Education for Learners with Mild Disabilities

Published 2000, 280 pages
Cheryl A. Utley & Festus E. Obiakor
$63.95, hard ISBN 0-398-07118-7
$41.95, paper ISBN 0-398-07119-5

VISUAL IMPAIRMENT IN THE SCHOOLS (3rd Ed.)

Published 2000, 262 pages
Randall K. Harley, G. Allen Lawrence, LaRhea Sanford & Rebecca Burnett
$47.95, cloth ISBN 0-398-07014-8
$34.95, paper ISBN 0-398-07015-6 (displayed)

BRIDGING THE FAMILY-PROFESSIONAL GAP
Facilitating Interdisciplinary Services for Children With Disabilities

Published 1999, 300 pages
Billy T. Ogletree, Martin A. Fischer & Jane B. Schulz
$51.95, cloth ISBN 0-398-06988-3
$38.95, paper ISBN 0-398-06989-1 (displayed)

DISABILITY AWARENESS IN THE CLASSROOM
A Resource Tool for Teachers and Students

Published 1999, 230 pages
Lorie Levison & Isabelle St. Onge
$40.95 spiral (paper) 0-398-06953-0

ACTIVITIES FOR CHILDREN IN THERAPY
A Guide for Planning and Facilitating Therapy with Troubled Children (2nd Ed.)

Published 1999, 302 pages
Susan T. Dennison & Connie M. Knight
$47.95, spiral (paper) ISBN 0-398-06971-9

Charles C Thomas • Publisher, Ltd. • P.O. Box 19265, Springfield, IL 62794-9265
Call 1-800-258-8980 or 1-217-789-8980 or Fax 1-217-789-9130
Complete catalog available at www.ccthomas.com • books@ccthomas.com

Books sent on approval • Shipping charges: $5.95 U.S. / Outside U.S., actual shipping fees will be charged • Prices subject to change without notice

Circle #36 or visit www.eparent.com/adinfo

"Imagine if Your Child Could Follow Instructions and Accept No"

When a child sustains a brain injury traditional treatment sometimes isn't enough. It takes a transdisciplinary team approach that includes a strong behavior program in addition to educational, medical, pharmacological and restorative therapies. The behavior program is directed towards restoring the child's self-control andself-image.

At the FLORIDA INSTITUTE FOR NEUROLOGIC REHABILITATION, INC., (FINR) our sole concern is brain injury rehabilitation and our pediatric/adolescent services and model school programs focuses on the kids "Getting better and having fun again." Individual Education Plans are a primary tool used to aid the children in reaching their academic potential.

BEHAVIORAL STRATEGIES
MANAGEMENT

The kids begin to complete tasks and families learn techniques needed in order to ensure appropriate follow through once discharge occurs.

Traditional settings and therapies are sometimes not enough so please call us and we can provide you and your child with the resources and staff expertise to insure a successful outcome.

Please use our toll free number and call us at 1-888-TBI FINR or log on to our web site at www.finr.org

Our qualified representatives are available nationally to conduct pre-screening field evaluations or schedule facility tours at no cost or obligation.

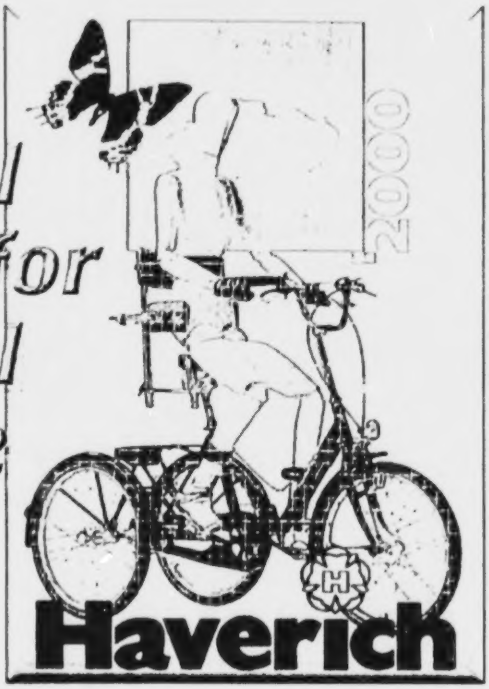
FLORIDA INSTITUTE FOR NEUROLOGIC REHABILITATION, INC.

1-800-697-5390 www.finr.org

artwork provided by pediatric resident © FLORIDA INSTITUTE FOR NEUROLOGIC REHABILITATION, INC.

Circle #58 or visit www.eparent.com/adinfo

Special Bikes for Special People



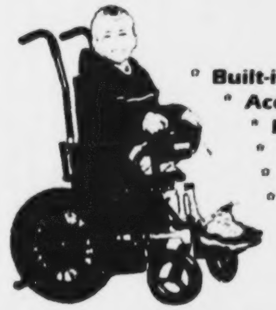
A wide choice of
bikes, colors and
adaptive equipment
for people with
special needs.

165 Martell Court, Keene, NH 03431
Tel: 603-358-0438 • Fax: 603-358-0453
www.haverich.com

Circle #71 or visit www.eparent.com/adinfo

The Starlight

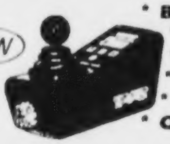
"Parent-Friendly"



- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW



- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Personalized Power Controller

Made in U.S.A.

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Circle #64 or visit www.eparent.com/adinfo

2 New Products

help promote independence
for adults and children who need assistance holding their dishes and drinks while eating.
No More Spills! No More Mess!

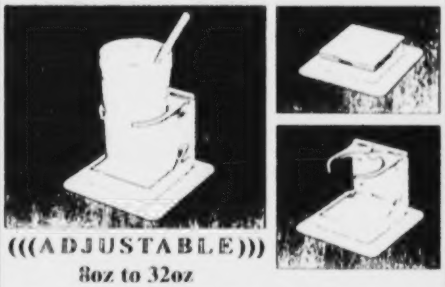
Cyber Dinnerware

...The won't move dinnerware

New FDA approved material probrilene™ won t break! won t chip! Microwave Yes! Dishwasher Yes!

Cyber Drink Holder

...The won't move drink holder



(((ADJUSTABLE)))
8oz to 32oz
For Bed Tables & Wheelchair Trays

Patented Cyber Pad Base is a unique suction power pad that sticks to any flat surface. Designed to securely hold the Cyber Dinnerware *and* Cyber Drink Holder

Hit It!... Push It!... Pull It!
Keep it clean and it won't move!
Lift corner of pad to remove it.

call us... 1 (877) FOR-CYBER
367-2923
see demonstration on internet
www.i-adl.com

Circle #76 or visit www.eparent.com/adinfo

INTERNATIONAL GUIDE TO MOVEMENT DISORDER PATIENT ADVOCACY GROUPS AND FOUNDATIONS

From WE MOVE (Worldwide Education and Awareness for Movement Disorders)

This guide provides a comprehensive listing of national, regional and international support organizations committed to improving the quality of life for people with movement disorders. They are arranged alphabetically by disease and by country. Some of these organizations have established support services with local chapter affiliates for individuals with specific movement disorders and their families. Many provide referrals, publish educational materials, host Web sites, raise funds and provide grant money for scientific research. (Please see the key to services on the bottom of every other page.) All of these organizations share a common goal: to facilitate accurate and timely diagnosis of movement disorders and access to up-to-date treatment. This listing also appears on the WE MOVE Web site (http://www.wemove.org), the Internet's most comprehensive resource for movement disorder information and activities.

WE MOVE is a not-for-profit organization committed to educating and informing healthcare professionals, people with movement disorders and the public about neurologic movement disorders. WE MOVE can assist those who wish to establish new organizations where no national group exists. For more information, please contact: WE MOVE, 204 W. 84th St. New York, NY 10024, USA; phone: (800) 437-6882 or (212) 875-8312; fax: (212) 875-8389, e-mail: wemove@wemove.org; Web site: http://www.wemove.org.

USING THIS DIRECTORY

When available, World Wide Web sites are listed with the standard http:// before each. (Unless otherwise indicated, all telephone numbers are for voice only.) *Editor's Note: Telephone numbers are listed after the words TEL:, fax numbers are after the word FAX:, e-mail addresses are indicated by the symbol ✉. Please note that since this directory contains international organizations, be sure to use 011 when dialing from the United States.*

ATAXIA/OLIVOPONTO-CEREBELLAR ATROPHY

AUSTRALIA

Friedreich's Ataxia Association of New South Wales
Chisholm Street 31a
Turramurra 2074
Australia
TEL: (61) 2 94408233
Web Site: http://www.faa.org.au

Spino Cerebellar Ataxia Resources & Support (SCARS)
7 Robilliard Street
Mays Hill 2145
Australia
✉michelle@bmu.net.au
Web Site: http://www.backmeup.net.au

BELGIUM

Association Belge de l'Ataxie de Friedreich et des autres Ataxies Hereditaires
Rue Longe 68
Bouffioulx B-6200
Belgium
Contact: Madeline Pelousse
TEL: (32) 71 50 42 48
FAX: (32) 71 50 42 48

European Federation of Hereditary Ataxias
Haagwindelaan 19
Overijse B-3090
Belgium
Contact: Dagmar Kroebel
TEL: (32) 2 657 1510
FAX: (32) 2 657 6176
✉dk.euro-ataxia@skynet.be
Web Site:
http://www.home.wanadoo.nl/euro-ataxia
***Resources**: n, br, sg*

CANADA

Canadian Assoc. of Friedrich's Ataxia
5620 C.A. Jobin Street
Montreal, Quebec H1P 1H8
Canada
Contact: Claude St-John
TEL: (514) 321-8684
FAX: (514) 321-9257
Web Site: http://www.cam.org
***Resources**: n, br, sg, rs, th, fe, rg*

FINLAND

Rare Neurological Disabilities Group
Suomen MS-Liitto - Finlands MS-Förbund
European Federation of Hereditary Ataxias (Euro-Ataxia)
Seppalantie 90
Masku FIN-21251
Finland
TEL: (358) 2 4392111
FAX: (358) 2 4392133
Web Site: http://www.ms-liitto.fi

FRANCE

Association Strumpell-Lorrain
European Federation of Hereditary Ataxias (Euro-Ataxia)
9 bis, rue Fabre
Besancon F-25000
France
TEL: (33) 3 81502391
FAX: (33) 3 81502391
✉asl.spastic@wanadoo.fr
Web Site: http://www.afaf.ree.fr
***Resources**: n, v, br, sg*

GERMANY

Deutsche Heredo-Ataxie Gesellschaft Bundesverband e.v.
European Federation of Hereditary Ataxias (Euro-Ataxia)
Haussmannstrasse 6
Stuttgart D-70188
Germany
TEL: (49) 711 2155114
FAX: (49) 711 2155214
Web Site: http://www.ataxie.de

IRELAND

Friedrich's Ataxia Society of Ireland
Mart Lane, San Martin
Dublin 18 ireland
Contact: Clare Creedon, San Martin
TEL: (353) 1289 47 88
Web Site: http://www.fasi.ie

ITALY

Associazione Italiana per la lotta alle Sindromi Atassiche
European Federation of Hereditary Ataxias (Euro-Ataxia)
Via Cattaneo 22
Magenta (MI) I-20013 Italy
TEL: (39) 2 9792271
✉aisa@iol.it
Web Site:
http://www.hosting.iol.it/aisa

SPAIN

Asociacion Madrilena de Ataxias Hereditarias
European Federation of Hereditary Ataxias (Euro-Ataxia)
C/. Galileo 69, 1
Madrid E-28015 Spain
TEL: (34) 1 4482169

SWITZERLAND

Schweizerische Gesellschaft fur Muskelkrankheiten
European Federation of Hereditary Ataxias (Euro-Ataxia)
Brinerstrasse 1, Postfach
Zurich 8036, CH-8046
Switzerland
Contact: Daniela Iser
TEL: (41) 1 466 6999
FAX: (41) 1 466 6990
Web Site: http://www.multiplesklerose.ch
***Resources**: n, v, br, ep, sg, rs, fe, rg*

THE NETHERLANDS

ADCA-Vereniging Nederland
Fazantenkamp 839
Maarssen, NL-3607 EC
The Netherlands
Contact: Marco Meinders
TEL: (31) 346 563913
FAX: (31) 346 580417
✉ataxie@ataxie.nl
Web Site: http://www.ataxie.nl

VSN - Werkgroep Ataxie van Friedreich
European Federation of Hereditary Ataxias (Euro-Ataxia)
Haagw, NL-2324 NC
The Netherlands
TEL: (31) 71 5320660
Web Site: http://www.vsn.nl

UK

Friedrich's Ataxia Group
European Federation of Hereditary Ataxias (Euro-Ataxia)
The Stable, Wiggins Yard, Bridge Street
Godalming, Surrey GU7 1HW
UK
Contact: Chris Polhill
TEL: (44) 1483 417111
FAX: (44) 1483 424006
Web Site:
http://www.ataxia.org/uk

USA

Ataxia MJD Research Project, Inc.
875 Mahler Road, Ste 161
Burlingame, CA 94010-1621
USA
Contact: Laura Denning
TEL: (650) 373-0674
FAX: (650) 342-8741
✉LDenning@ataxiamjd.org
Web Site:
http://www.ataxiamjd.org

National Ataxia Foundation
2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447-4752
USA
Contact: Donna Gruetzmacher
TEL: (763) 553-0020
FAX: (763) 553-0167
✉naf@mr.net
Web Site: http://www.ataxia.org
***Resources**: n, v, br, bk, ep, sg, pp, rs, fe, rg*

DYSTONIA

AUSTRALIA

Australian Spasmodic Torticollis Association
PO Box 133
Westmead, New South Wales 2145
Australia
Contact: Annette Walker
TEL: (61) 296 859 020
FAX: (61) 296 859 599
✉a.walker@uws.edu.au
***Resources**: n, sg*

Blepharospasm Support Group
Royal Victorian Eye & Ear Hospital, 32 Gisborne Street
East Melbourne, Victoria 3002
Australia
TEL: (61) 3 9929 8666
FAX: (61) 3 9663 7203
✉jpritchard@rveeh.vic.gov.au

Spasmodic Dysphonia Support Group
8 Corona Avenue
Roseville, New South Wales 2069
Australia
Contact: Cynthia Turner
TEL: (61) 294 112 424
FAX: (61) 294 112 424
***Resources**: n, er, br, ep, sg, pp, rs, th*

AUSTRIA

Österreichische Dystonie Gesellschaft
Austrian Dystonia Association
Vorgartenstrasse, Vienna A 1020
Austria
Contact: Christa Hafenscher
TEL: (43) 1219 7161
FAX: (43) 1219 7161

KEY TO SERVICES

n	newsletter
v	video tape
a	audio tape
er	educator's resource materials
br	brochure, fact sheet
bk	book
ep	educational program
sg	support group meeting
pp	"Pen Pal" network
rs	referral service
th	telephone "hotline"
fe	fundraising event
rg	research grant

BELGIUM

Belgische Zelphulpgroep Voor Dystonie Patiënten
Belgian Dystonia Association
Blokmakerstraat 6
Haasdonk 9120
Belgium
Contact: Christine Wauters
TEL: (32) 3 7755125
FAX: (32) 3 7755125

BRAZIL

Associacao Brasileira dos Portadores de Distonias
Brazilian Dystonia Society
Al. Joaquim Eugenio de Lima, 870
apto. 41
Sao Paolo, SP Cep: 01403-000
Brazil
Contact: Henita Ferreira de Macedo
TEL: (55) 11 288 7032
FAX: (55) 11 228 7032
Resources*: *br, sg, rs, th

CHILE

Fundacion Distonia
Dystonia Foundation of Chile
Av. Irarrazaral 5185, Of. 311
Nunoa, Santiago, Chile
Contact: Benedicte De Pauw
TEL: (56) 22268874
FAX: (56) 22267346
Resources: n, br, ep, sg, rs, le

CROATIA

Hrvatska Grupa Za Istrazivanje Distonije
Croatia Dystonia Association
University of Zagreb, Kispaticeva 12
Zagreb, 10000 Croatia
Contact: Prof. Maja Relja
TEL: (385) 1 2388 377
FAX: (385) 1 7345 595

DENMARK

Dansk Dystoniforening
Danish Dystonia Association
Soihojpark 16
Farum, DK - 3520
Denmark
Contact: Ulla Balser Poulsen
TEL: (45) 4495 5165
FAX: (45) 4495 5165
✉ullafarum@teliamail.dk
Web Site: http://www.dystoni.dk

EUROPEAN

European Dystonia Federation
46/47 Britton Street
London ECIM 5UJ
UK
Contact: Alan Leng
TEL: (44) 20 7490 5671
FAX: (44) 20 7490 5672

FINLAND

Finnish Dystonia Association
Ostjakinkatu 5 as 29
Turku 20750 Finland
Contact: Liisi Niemi
TEL: (358) 92 792 738
✉liisi.niemi@pp.inet.fi
Web Site: http://www.dystoniayhdistys.com

FRANCE

Association de Malades atteints de Dystonie (AMADYS)
Le Lac
Saint-Paulien 43350 France
Contact: Robert Perbet
TEL: (33) 471 00 46 15
FAX: (33) 471 00 45 49
✉robert.perbet@wanadoo.fr
Web Site:
http://www.perso.wanadoo.fr/amadys/
Resources*: *n, br, sg, rgj

Ligue Francaise contre la Dystonie
27 rue du Bout des Creuses
Draveil 91210 France
TEL: (33) 169 83 23 39
FAX: (33) 169 83 23 39
✉lfcd@wanadoo.fr
Web Site:
http://www.perso.wanadoo.fr/lfcd/
Resources*: *n, br, bk, ep, sg, pp, th

GERMANY

Bundesverband Torticollis e. V.
Eckernkamp 39
Hamm 59077 Germany
Contact: Helga Weber
TEL: (49) 2389 53 69 88
FAX: (49) 2389 53 62 89
✉BVTorti@aol.com
Resources*: *n, sg

Deutsche Dystonie Gesellschaft e. V.
German Dystonia Association
Bockhorst 45 A
22589 Hamburg
Germany
Contact: Didi Jackson
TEL: (49) 40 87 56 02
FAX: (49) 40 87 08 28 04
✉Deutsche-Dystonie@t-online.de
Web Site: http://www.dystonie.de
Resources*: *n, br, sg, rs, pp, le, rg

IRELAND

Dystonia Ireland
33, Larkfield Grove- Harold's Cross
Dublin 6W Ireland
Contact: Maria Hickey
TEL: (353) 1 4922514
FAX: (353) 1 4922565
✉info@dystonia.ie
Web Site: http://www.dystonia.ie

ITALY

Assoc. Italiana per la Ricerca Sulla Distonia
Italian Dystonia Association
Via Arturo Colautti 28
Rome 00152 Italy
Contact: Nadia Trinci
TEL: (39) 06 589 8727
FAX: (39) 06 580 3940
✉info@distonia.it
Web Site: http://www.distonia.it
Resources*: *n, br, bk, rs, th, le

NEW ZEALAND

NZ Spasmodic Dysphonia Patients' Network
15 Pluto Place
North Shore City, Auckland 1310
New Zealand
Contact: David Barton
TEL: (64) 9 482 1567
FAX: (64) 9 482 1284
✉dsbarton@ihug.co.nz
Resources*: *n, br, sg

NORWAY

Norsk Dystoniforening
Norwegian Dystonia Association
Ingebjørg Mælandsmosveg 18
Notodden N-3676
Norway
Contact: Tore Wirgenes
TEL: (47) 35 02 05 38
FAX: (47) 35 02 05 38
✉norsk.dystoni.forening@online.no
Web Site: http://www.home.online.no/~wirgeme/
Resources*: *n, br, sg

SERBIA

Yugoslav Dystonia Association
Institute of Neurology, Dr. Subotica Nr. 6
Belgrade 11000
Serbia
Contact: Dr. Marina Svetel
TEL: (381) 11 689 554
FAX: (381) 11 684 577
✉ marinas@imi.bg.ac.yu
Resources*: *n, br, ep, sg, rs, th

SLOVENIA

Dystonia Association of Slovenia
Institute of Clinical Neurophysiology, University Medical Centre
Ljubljana 1525
Slovenia
Contact: Dr. Zvezdan Pirtosek
TEL: (38) 661 316 152
FAX: (38) 661 302 771
Resources*: *n, v, er, br, ep, sg

SOUTH AFRICA

Dystonia Association South Africa
PO Box 3160
Pinegowrie 2123
South Africa
Contact: Maureen Langford
TEL: (27) 11 787 8792
FAX: (27) 11 787 2047
Email: dystonia@global.co.za
Resources*: *n, v, br, sg, th, le

SPAIN

Asoc. de Lucha contra la Distonia en España
Spainish Dystonia Society
c/ Galileo, 69-1
Madrid 28015
Spain
Contact: Begoña Paris
TEL: (34) 91 5940066
FAX: (34) 91 5940066
✉alde@distonia.org
Web Site:
http://www.distonia.org
Resources*: *n, v, er, bk, sg, rs, th

SWEDEN

Svensk Dystoni Forening
Swedish Dystonia Society
Stjarngossevagen 108
Alvsjo 125 35
Sweden
Contact: Anders Silfors
TEL: (46) 8999956
FAX: (46) 8999956
Web Site:
http://www.dystoni.com
Resources*: *n, er, r, sg, th

SWITZERLAND

Schweizerische Dystonie Gesellschaft
Swiss Dystonia Association
Tramstrasse 39
Muttenz CH - 4131
Switzerland
Contact: Dr. Brigitte Gygli
TEL: (41) 614 616 993
FAX: (41) 614 616 993
Resources*: *n, v, br, ep, sg

THE NETHERLANDS

Nederlanse Verening van Dystoniepatienten
Netherlands Dystonia Association
Postbus 9345
Breda 4801 LH
The Netherlands
Contact: Louis Beduwe
TEL: (31) 76 514 0765
FAX: (31) 76 521 6495
Resources*: *n, br, bk, sg, pp

UK

The Dystonia Society
46/47 Britton Street
London EC1M 5UJ
UK
Contact: Alan Leng
TEL: (44) 20 7490 5671
FAX: (44) 20 7490 5672
Web Site:
http://www.dystonia.org.uk
Resources*: *n, v, er, br, ep, sg, pp, rs, th, le, rg

USA

Benign Essential Blepharospasm Research Foundation, Inc.
PO Box 12468
Beaumont, Texas 77726-2468
USA
Contact: Mary Lou Thompson
TEL: (409) 832-0788
FAX: (409) 832-0890
✉bebrf@ih2000.net
Web Site:
http://www.blepharospasm.org/
Resources*: *n, v, a, br, bk, sg, rs, rg

Care4Dystonia, Inc
Care for Dystonia
440 East 78th Street
New York, NY10021
USA
Contact: Beka Serdans, RN
TEL: 212-249-2808
✉bekadys@aol.com
Web Site:
http://www.care4dystonia.org/

Dystonia Medical Research Foundation
One East Wacker Drive, Suite 2430
Chicago, IL 60601-1905
USA
Contact: Valerie Levitan, PhD
TEL: (312) 755-0198 in Canada (800) 361-8061
FAX: (312) 803-0138
✉dystonia@dystonia-foundation.org
Web Site: http://www.dystonia-foundation.org/
Resources*: *n, v, a, er, br, bk, ep, sg, pp, rs, th, le, rg

National Spasmodic Dysphonia Association
One E. Wacker Drive, Suite 2430
Chicago, IL 60601-1905
USA
Contact: Valerie Levitan, PhD
TEL: (800) 795-NSDA
FAX: (312) 803-0138
✉NSDA@dysphonia.org
Web Site:
http://www.dysphonia.org
Resources*: *n, v, br, sg, pp, rg

National Spasmodic Torticollis Association
9920 Talbert Avenue #233
Fountain Valley, CA 92708
Contact: Diane Truong
TEL: 800-HURTFUL
✉nstamail@aol.com
Web Site:
http://www.torticollis.org

Spasmodic Torticollis/ Dystonia, Inc.
P.O. Box 28
Mukwonago, WI 53149
USA
Contact: Howard Thiel
TEL: 1-888-445-4598
✉info@spasmodictorticollis.org
Web Site: http://www.spasmodictorticollis.org.

The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc.
One Gustave L. Levy Place, Box 1490
New York, NY 10029
USA
Contact: Bonnie Strauss
TEL: (212) 241-5614
FAX: (212) 987-0662
✉Bachmann.Strauss@mssm.edu
Web Site: http://www.dystonia-parkinsons.org
Resources*: *br, ep, le, rg

HUNTINGTON'S DISEASE

AUSTRALIA

Australian HD Association
PO Box 178
West Ryde
New South Wales 2114
Australia
Contact: Robyn Kapp
TEL: (61) 298 749 777
FAX: (61) 298 749 177
✉robynk@ahdansw.bu.aust.com
Web Site:
http://www.home.vicnet.net.au/~ahda

INTERNATIONAL GUIDE TO MOVEMENT DISORDER PATIENT ADVOCACY GROUPS AND FOUNDATIONS

From WE MOVE (Worldwide Education and Awareness for Movement Disorders)

AUSTRIA

Oestereichische Huntington Hilfe
Hasnerstrasse 88/23
Vienna 1160
Austria
TEL: (43) 149 291 53
✉stock@merlin ap univie ac at

BELGIUM

Huntington Liga
Krijkelberg 1
Bierbeek B 3360
Belgium
TEL: (32) 1645 27 59
FAX: (32) 1645 30 60

Ligue Huntington Francophone Belge
4b, Montagne Ste Walburge
Liege 4000, Belgium
TEL: (32) 4 225 87 33
FAX: (32) 4 225 87 33
✉huntington@multimania.com
***Resources:* v, br, sg, th**

BRAZIL

Associacao Huntington Brazil
Rua Das Camelias 38, Jardim Imperial
Atibaia, SP 12940-000
Brazil
TEL: (55) 11 484 2199
FAX: (55) 11 484 2199
✉hdbr@latinmail.com
Web Site: http://www.abh org br

CANADA

Huntington Society of Canada
151 Fredrick Street, Suite 400
Kitchener, Ontario N2H 2M2
Canada
TEL: (519) 749-7063
FAX: (519) 749-8965
✉info@hsc-ca.org
Web Site: http://www.hsc-ca.org
***Resources:* n, v, em, br, sg, fe, rg**

Huntington Society of Quebec
4841 Rivard Street
Montreal, Quebec H2J 2N7
Canada
TEL: (514) 842 5740
FAX: (514) 842 5961
✉shq@total.net

CZECH REPUBLIC

Spolecnost Pro Pomoc Pri Huntingtonove Chorobe
Dolni Brezany 153
Prague-West 25241
Czech Republic
Contact: Dr. Jana Zidovska
TEL: (42) 224 90 4261
FAX: (42) 229 49 05
***Resources:* n, br, ep, sg, rs**

DENMARK

Landsforeningen Mod Huntington's Chorea, LHC
Danish Huntington Patients' Association
Havnøvej 3
Havnø, Hadsund 9560
Denmark
Contact: Merete L\0x9Fttichau
TEL: (45) 9857 5323
FAX: (45) 9857 3496
✉Merete.Luttichau@image.dk
Web Site: http://www.mmm.uni-c.dk/lhc/
***Resources:* n, v, br, bk, ep, sg, rs**

FINLAND

Huntington Association of Finland
The Family Feseration of Finland/Vaestoliitto
Kalevankatu 16a
Helsinki 00101 Finland
TEL: (358) 0 6162 2246
FAX: (358) 0 645 018
✉marjatta.sipponen@vaestoliitto.fi

FRANCE

Association Huntington France
42, 44 rue du Chateau des Rentiers
Paris 75013 France
TEL: (33) 1 5360 0879
FAX: (33) 1 5360 0899
✉mopahf@club-internet.fr

GERMANY

Deutsche Huntington Hilfe
Postfach 281251
Duisburg D47241 Germany
Contact: Georg Hirschler
TEL: (49) 203 229 15
FAX: (49) 203 229 25
✉dhh@dhh-ev.de
Web Site: http://www.dhh-ev.de

INDIA

Huntington's Organization
K 18/7 Dlf Qutub Enclave Phase II
Gurgaon
Haryana 35-66-77 India
Contact: Ms. Mano Singh
TEL: (91) 124 356 677
FAX: (91) 124 351 945
✉bgmehra.vsnl com

INTERNATIONAL ASSOCIATION

International Huntington Association
Callunahof 8
Harfsen 7217 ST
The Netherlands
Contact: Gerrit R. Dommerholt
TEL: (31) 573 431595
FAX: (31) 573 431719
✉iha@huntington-assoc.com
Web Site: http://www.huntington-assoc.com

IRELAND

Huntington's Disease Association of Ireland
Carmichael Centre,
N. Brunswick St
Dublin 7 Ireland
Contact: Bernadette Moran
TEL: (353) 187 213 03
FAX: (353) 187 357 37
✉hdai@indigo.ie
Web Site:
http://www.indigo.ie/~hdai
***Resources:* n, v, a, br, bk, ep, sg, pp, rs, th, rg**

ISRAEL

Israeli Huntington Disease Support Group
3 Lubezky St.
Gedera 70700 Israel
TEL: (972) 8 859 8573
***Resources:* n, br, sg**

ITALY

Associazione Italiana Corea di Huntington
Via L. Ariosto 19
Milano 20145 Italy
Contact: Gabriella Conte Marotta
TEL: (39) 24801 5529
FAX: (39) 2239 4448
Web Site:
http://www.freeweb.org/salute/aich/index.htm
***Resources:* n, br, bk, sg, th, fe, rg**

Associazione Italiana Corea di Huntinton - Napoli
Clinica Neurologica -Ed. 17, Via Pansini 5
Napoli 80131 Italy
Contact: Policlinio Fererico II
TEL: (39) 81 5455 213/7462 693
FAX: (39) 81 7462 373

JAPAN

Japan Huntington's Disease Network
The Health Care Science Institute,
3-2-12 5F Akasaka
Minato-Ku, Tokyo 107-0052
Japan
Contact: Dr. Kaori Muto Yamamoto
TEL: (81) 3 5563 1791
FAX: (81) 3 5563 1795

MALTA

Maltese Huntington's Association
Dept. of Anatomy, University of Malta
Msida MSD 06 Malta
Contact: Prof. Alfred Cuschieri
TEL: (356) 329 022 80
FAX: (356) 319 527

MEXICO

Asociacion Mexicana de la Enfermedad de Huntington A.C.
San Carlos #51, San Angel Inn
San Carlos DF CP 01060
Mexico
TEL: (52) 5 550 02 11
FAX: (52) 5 550 76 26
***Resources:* v, er, br, bk, ep, sg, rs, fe**

NEW ZEALAND

Huntington's Disease Association
PO Box 78, Cust
North Canterbury
Cust 2500 GL New Zealand
Contact: Judith Baker
TEL: (64) 3 3125 612
FAX: (64) 4 3485 442
Web Site:
http://www.voyager.co.nz/~huntnz/
***Resources:* v. er, br, bk, sg, fe**

NORTHERN IRELAND

Huntington's Disease Assoc. of N. Ireland
Floor A. West Podium Extension,
Tower Block, Belfast City Hospit
Belfast BT9 7AB Northern Ireland
Contact: Dept. of Medical Genetics
TEL: (44) 28 90 263 555
FAX: (44) 28 90 236 911
***Resources:* v, bk, sg, rs, fe**

NORWAY

Landsforeningen for Huntington's Sykdom
Postbox 103
Oppegard N 1415 Norway
Contact: Sigrun Rosenlund
TEL: (47) 66 992477
FAX: (47) 66 993431
***Resources:* n, v, er, br, sg, rs, th**

PAKISTAN

Huntington Disease Care & Cure Society of Pakistan
2 Sawati Gate
Peshawar Cantt
Pakistan
Contact: Dr. Asif Kahn
TEL: (92) 5212 75471
FAX: (92) 5212 77583
***Resources:* n, v, er, br, sg, rs, th**

PORTUGAL

Associacao Portguesa da Doenga de Huntington
Rue Dr. Alfonso Costa, 32
Alvor-Portimao P 8500 Portugal
Contact: Mrs. Ursula-Anna Kleibrink
TEL: (351) 82 459331
FAX: (351) 82 459337
✉op207@mail.telepac.pt
Web Site:
http://www.terravista.pt/guincho/5388/preview/index.html

RUSSIA

Huntington Association of Russia
Volokolamskoye Shosse 80
Moscow 123367 Russia
Contact: Inst. of Neurology; AC Science
TEL: (795) 490 2103/490 2039
FAX: (795) 490 2210
✉nnikolskaya@hotmail.com

SCOTLAND

Scottish Huntington's Association
Thistle House, 61 Main Road
Elderslie PA5 9BA Scotland
Contact: Ann Carruthers
TEL: (44) 1505 3222 45
FAX: (44) 1505 3829 80
✉sha-admin@hdscotland.org
Web Site: http://www.hdscotland.org
***Resources:* n, v, er, br, bk, sg, rs, fe**

SLOVAKIA

Spolecnost Pre Pomoc Pri Huntindonoveg Chorobe V Slovenskej
Slovakian Huntington Society
Republike Oddelinie Lekarskej Genetiky
Banska Bystrica 97517 Slovakia
TEL: (42) 88 713 380
FAX: (42) 88 320 65
✉mkva@gnp.cis.upenn.edu

SLOVENIA

Huntington Association of Slovenia, i.e.
Ciglence, 9
Spodnji Duplek 2241 Slovenia
Contact: Mr. Bogomir Mursec
TEL: (386) 62 681 221

SOUTH AFRICA

Huntington's Society of South Africa
PO Box 44501, Claremonte
Cape Town 7735 South Africa
TEL: (27) 21 91 100 36
FAX: (27) 21 91 100 36
✉jschron@iafrica.com
***Resources:* n, ep, sg, fe**

SPAIN

Asociacion de Corea de Huntington Espanola (A.C.H.E.)
Servicio Neurologia, Fundacion Jimenez Diaz, Avda Reyes Catolico
Madrid 28040 Spain
Contact: Asuncion Martinez
TEL: (34) 91 544 9008
FAX: (34) 91 549 7381
✉amartinez@fjd.es
Web Site: http://www.e-huntington.tripod.com
***Resources:* n, br, bk, rs, th, fe**

Associacio Catalana de Malalts de Huntington (ACMAH)
Hotel d'Entitats de la Pau, c/Pere Verges 1, Desp 7-1
Barcelona 08020 Spain
TEL: (34) 93 314 5657
FAX: (34) 93 314 5657
✉acmah.b@suport.org

SWEDEN

Huntington Foreningen I Sverige
c/o NHR, Postbox 3284,
Kungsgatan 32
Stockholm 10365 Sweden
Contact: Mia Lundstrom
TEL: (46) 8 677 7010
FAX: (46) 8 24 1315
✉mia.lundstrom@nhr.se

SWITZERLAND

Schweizerische Huntington Vereinigung
Swiss Huntington Association
Bahnweg 4
Oberhasli CH 8156 Switzerland
Contact: Heidy Moser Welti
TEL: (41) 1 885 19 41
FAX: (41) 1 885 19 44
✉info@shv.ch
Web Site: http://www.shv.ch

KEY TO SERVICES

n	newsletter
v	video tape
a	audio tape
er	educator's resource materials
br	brochure, fact sheet
bk	book
ep	educational program
sg	support group meeting
pp	"Pen Pal" network
rs	referral service
th	telephone "hotline"
fe	fundraising event
rg	research grant

THE NETHERLANDS

Vereniging Van Huntington
Postbox 30470
Den Haag 2500 GL
The Netherlands
TEL: (31) 70 314 8888
FAX: (31) 70 314 8880
✉info@huntington.nl
Web Site: http://www.huntington.nl

UK

Huntington's Disease Association
108 Battersea High St
London SW11 3HP UK
TEL: (44) 207 223 7000
FAX: (44) 201 223 9489
✉info@hda.org.uk
Web Site: http://www.hda.org.uk

The Huntington Society
1 Rose Lea Close, Hillam
Yorkshire LS25 5HJ UK
Contact: Malcolm Pattman
TEL: (44) 1924 280 062
FAX: (44) 1924 263 950

USA

Huntington's Disease Society of America
158 West 29th Street, 7th Floor
New York, NY 10001-5300
USA
Contact: Barbara T. Boyle
TEL: (800) 345-HDSA / (212) 242-1968
FAX: (212) 239-3430
✉hdsainfo@hdsa.org
Web Site: http://www.hdsa.org
***Resources**: n, v, br, bk, ep, sg, rs, th, fe, rg*

MULTIPLE SYSTEM ATROPHY

UK

The Autonomic Disorders Association Sarah Matheson Trust
St. Mary's Hospital, Praed Street
London W2 1NY UK
Contact: Imperial College School of Medicine
TEL: (44) 207 8 861 520
FAX: (44) 207 8 861 540

USA

Shy-Drager/Multiple System Atrophy Support Group Inc.
2004 Howard Lane
Austin, TX 78728
USA
Contact: Don Summers
TEL: 866-737-4999
FAX: 512-251-3315
✉Don.Summers@shy-drager.com
Web Site: http://www.shy-drager.com

MYOCLONUS

USA

Moving Forward
2934 Glenmore Avenue
Kettering, OH 45409
USA
Contact: Pauline Dill
TEL: (513) 293-0409

Myoclonus Families United
155 E. 35th Street
Brooklyn, NY 11234
USA
Contact: Sharon Dobkin
TEL: (718) 252-2133

Myoclonus Research Foundation
200 Old Palisade Road, Suite 17D
Fort Lee, NJ 07024
USA
Contact: Theodora Mason
TEL: (201) 585-0770
FAX: (201) 585-8114
Web Site:
http://www.myoclonus.com
***Resources**: v, br, rg*

PARKINSON'S DISEASE

ARGENTINA

Grupo de Autoayuda Parkinson Argentina
Fundacion Alfredo Thomson, La Rioja 951
Buenos Aires 1221 Argentina
Contact: Ana Gimenez de Piol
TEL: (54) 1956 0120
FAX: (54) 1956 0120
***Resources**: n, a, br, ep, sg, rs*

AUSTRALIA

Parkinson's Australia, Inc.
Concord RG Hospital, Bldg. 64, Hospital Rd.
Concord NSW 2139 Australia
Contact: c/o Parkinson's NSW, Inc.
***Resources**: n, v, br, sg, fe*

AUSTRIA

Parkinson Selbsthilfeverein Oberosterreich
Bindergraben 4
Katsdorf 4223 Austria
Contact: Reinhard Hinterleitner
TEL: (43) 7235 82 84
***Resources**: n, th*

BRAZIL

Associacao Brasil Parkinson
PO Box 3168, Fortaleza
Ceara 60431-970 Brazil
Contact: Dr. Wagner Horta
TEL: (55) 852 573 011
FAX: (55) 852 617 822

CANADA

Parkinson Foundation of Canada-National Office
4211 Yonge Street, Suite 316
Toronto, Ontario M2P 2A9
Canada
Contact: Mary Jardine
TEL: (416) 227-9700 or 800-565-3000
FAX: (416) 227-9600
Web Site:
http://www.parkinson.ca
***Resources**: n, v, er, br, bk, ep, sg, th, fe, rg*

CHILE

Liga Chilena Contra el Mal de Parkinson
Arturo Prat 1341
Santiago, Chile
Contact: Dr. Pedro Chana
TEL: (55) 2555 7716
FAX: (55) 2555 7716
✉ pchana@itn.cl
Web Site:
http://www.andronet.cl/parkinson/
***Resources**: n, v, a, er, bk, ep, sg, rs, th*

CZECH REPUBLIC

Parkinson's Disease Society
Ruska 69
Prague 10
10000
Czech Republic
TEL: (42) 274 42 38

DENMARK

Dansk Parkinsonforening
Hornemansgade 36
Koebenhavn OE DK2100
Denmark
Contact: Vibeke Joergensen
TEL: (45) 3927 1555
FAX: (45) 3918 2075
✉dansk@parkinson.dk

EUROPEAN

European Parkinson's Disease Assoc.
215 Vauxhall Bridge Road
London SW1V 1EJ UK
Contact: Liz Graham, EPDA Liason
TEL: (44) 207 931 8080
FAX: (44) 207 233 9226
✉ Lizzie@epda.demon.co.uk
Web Site:
http://www.shef.ac.uk/misc/groups/epda/home.html
***Resources**: n, v, er, br, bk, ep, sg, pp, rs, th, rg*

FINLAND

Finlands Parkinsonforbund
Suomen Parkinson-litto, PB 905
Turku 20101 Finland
Contact: Brita Nybom
TEL: (358) 2 2740 400
FAX: (358) 2 2740 444
✉Brita.Nybom@parkinson.fi
Web Site: http://www.parkinson.fi

FRANCE

Association de Groupments de Parkinsoniens
3 Chemin du Grand Fosse
St. Nazaire 44600 France
Contact: Marcel Besnard
TEL: (33) 4022 00 84

Association France Parkinson
37 bis rue la Fontaine
Paris 75016 France
Contact: Alain Honorat
TEL: (33) 145 202 220
FAX: (33) 140 501 644
***Resources**: n, br, bk, ep, sg, rs, th, rg*

GERMANY

Deutsche Parkinson Vereinigung Bundesverband e.V.
Moselstrasse 31
Neuss 41464 Germany
Contact: Friedrich Mehrhoff
TEL: (49) 213 141 016/7
FAX: (49) 213 145 445
***Resources**: n, v, a, er, br, bk, ep, sg, rs, th, fe, rg*

ICELAND

Parkinsonsamtokin a Islandi
The Parkinson Association of Iceland
Postbox 10182
Reykjavik 101 Iceland
Contact: Oskar Konradsson, Chairman
TEL: (354) 127 417
✉parkinson@simnet.is
Resources: n, br, sg

INDIA

Parkinson's Disease Society of Karnataka
No. 633, 3rd Cross, HMT Layout, RT Nagar
Bangalore 50032 India
Contact: Mr. Arun Kumar
TEL: (91) 80 3439038

Parkinson's Foundation of Bombay
Jaslok Hospital & Research Ctr
12th Floor, Pedder Road (Bulbhai)
Bombay (Mumbai)
Maharashtra 400 026 India
Contact: Dr. Mohit Bhatt
TEL: (91) 22 493 3333 (x340)
FAX: (91) 22 494 8008
***Resources**: ep, sg, rs*

Parkinsons Disease Foundation and Research Association
214-A, Talwandi
Kota
Rajasthan, India
Contact: Mr. C. R. DAS
TEL: (92) 744 421 966
FAX: (92) 744 427 759
✉iaaskot@jpl.dot.net.in

IRELAND

Parkinson's Association of Ireland
Carmichael House, North Brunswick St.
Dublin 7 Ireland
TEL: (353) 187 222 34
FAX: (353) 187 354 34
***Resources**: n, sg, th, fe, rg*

ITALY

Associazione Italiana Parkinsoniani
Via Zuretti 35
Milano 20125 Italy
Contact: Marzio Piccinini
TEL: (39) 266 671 31111
FAX: (39) 267 05283
Email: aip@planet.it
Web Site:
http://www.acme.it/aip/
***Resources**: n, v, br, sg, pr, th, fe, rg*

Parkinson Italia
Italian Parkinson's Association
Piazza IV Novembre, 6
Milano 20124 Italy
Contact: Lucilla Bossi
TEL: (39) 02 669 79 85
FAX: (39) 02 67 07 00 73
✉lu.bossi@libero.it
Web Site: http://www.parkinson-italia.it

JAMAICA

Parkinson's Society of Jamaica
7 Glendon Circle, Hope Pastures
Kingston 6 Jamaica
Contact: David Mostyn
TEL: (809) 972-2236 or 92

JAPAN

Japan Parkinson Disease Association
1-9-13-812, Akasaka, Minato-ku
Tokyo, Japan
Contact: Hiro Sekine
TEL: (3) 3560 3355
FAX: (3) 3560 3356
✉jpda@mud.biglobe.ne.jp
***Resources**: n, bk, ep, th*

LUXEMBOURG

Association Luxembourgeoise de la Maladie de Parkinson
169 Avenue de la Liberation
3850 Schifflange
3850 Luxembourg
Contact: Junker Jean
TEL: (352) 546 221

MEXICO

Mexican Parkinson Disease Association
AMPAC, Apdo. Postal 27003
Col. Roma Sur
D.F. 06761 Mexico
Web Site: http://www.ampac-parkinson.org.mx

NEW ZEALAND

Parkinsonism Society of New Zealand, Inc.
PO Box 10 392
Wellington, New Zealand
Contact: Bruce J. Cutfield
TEL: (64) 4 472 2796
FAX: (64) 4 472 2162
✉parkinsonsnz@xtra.co.nz
***Resources**: n, v, a, er, br, bk, sg, pp, rs, fe*

NORWAY

Norges Parkinsonforbund
Schweigaardsgt. 34, bygg F, oppg. 2
Oslo 0191 Norway
Contact: Frank Marring
TEL: (47) 22 175 861
FAX: (47) 22 175 862
***Resources**: n, br, bk*

PERU

Asociacion Peruana Para La Enfermedad De Parkinson
Rousseau 488
Lima 41 Peru
Contact: Dr. Carlos Cosentino
TEL: (511) 4361113
✉cosenti@terra.com.pe
***Resources**: n, br, sg*

INTERNATIONAL GUIDE TO MOVEMENT DISORDER PATIENT ADVOCACY GROUPS AND FOUNDATIONS

From WE MOVE (Worldwide Education and Awareness for Movement Disorders)

PUERTO RICO

Asociacion Puertorriquena de Parkinson, Inc.
PO Box 66
Carolina 00986-0066 Puerto Rico
Contact: Iris Sanchez
TEL: (?) 246-5000

SLOVENIA

Parkinson's Disease Association of Slovenia
Institute of Clinical
Neurophysiology, University
Medical Centre
Ljubljana 1525 Slovenia
Contact: c/o Dr. Zvezdan Pirtosek
TEL: (38) 661 316 152
FAX: (38) 661 302 771

SOUTH AFRICA

Parkinson Association South Africa
Private Bag x36
Bryanston 2021 South Africa
Contact: Maureen Langford
TEL: (27) 11 787 87892
FAX: (27) 11 787 2047
✉parkins@global.co.za
Resources*: *n, v, a, er, br, bk, sg, th

SPAIN

Parkinson España
C/ de la Torre, 14 bajos
Barcelona 08006 Spain
Contact: Maria Jose Ruiz
TEL: (34) 34 160 320
FAX: (34) 34 161 060
Resources*: *n, v, a, bk, ep, sg, rs, th, rg

SWEDEN

Swedish Parkinson's Association
Karlagatan 23
Goteborg 41661 Sweden
Contact: Filip Garstam
TEL: (46) 31 193 020
FAX: (46) 31 190 245

KEY TO SERVICES

n	newsletter
v	video tape
a	audio tape
er	educator's resource materials
br	brochure, fact sheet
bk	book
ep	educational program
sg	support group meeting
pp	"Pen Pal" network
rs	referral service
th	telephone "hotline"
fe	fundraising event
rg	research grant

SWITZERLAND

Schweizerische Parkinsonvereinigung
Swiss Parkinson Association
gewerbestrasse 12a, postfach 123
Zurich CH-8132 Egg
Switzerland
Contact: Lydia Schiratzki
TEL: (41) 1984 01 69
FAX: (41) 1984 03 93
✉info@parkinson.ch
Web Site:
http://www.parkinson.ch
Resources*: *n, v, a, er, br, bk, ep, sg, rs, th, fe

THAILAND

Thai Parkinson's Disease Society
Pramongkutklao Army Hospital,
315 Rajvithee Rd.
Phyathai, Bangkok 10400
Thailand
TEL: (662) 245 5526
FAX: (662) 245 5526

THE NETHERLANDS

Parkinson Patienten Vereniging
Postbus 46
Bunnik, 3980 CA
The Netherlands
Contact: Aaron Heijman
TEL: (31) 340 561 369
FAX: (31) 340 571 306
Resources*: *n, v, br, bk, ep, sg, pp, rs, th, rg

TURKEY

Turkish Parkinson's Disease Society
Istanbul Univ., Cerrahpasa Med.
School, Dept. of Neurology
Istanbul 34303 Turkey
Contact: Prof. Dr. Sibel
Ozekmekci
TEL: (90) 212 588 3770
FAX: (90) 212 588 3770
✉sibeloz@superonline.com

UK

EKBOM Support Group
18 Rodbridge Drive
Thorpe Bay
Essex SS1 3DS UK
Contact: Mrs Eileen Gill
TEL: (44) 1702 582002
✉gill@ekbom-88.demon.co.uk

Parkinson's Disease Society
215 Vauxhall Bridge Road
London SW1V 1EJ UK
Contact: Mary Baker
TEL: (44) 207 931 8080
FAX: (44) 207 233 9226
Resources*: *n, v, a, br, ep, sg, th, fe, rg

USA

American Parkinson's Disease Assoc., Inc.
1250 Hylan Boulevard
Staten Island, NY10305
USA
Contact: G. Maestrone
TEL: (800) 223-2732 or (718) 981-8001
FAX: (718) 981-4399
Web Site: http://www.apda-parkinson.org
Resources*: *n, v, br, ep, sg, rs, th, fe, rg

Michael J. Fox Foundation for Parkinson's Research
Grand Central Station,
P.O. Box 4777
New York, NY10163
USA
Web Site:
http://www.michaeljfox.org

National Parkinson Foundation, Inc.
1501 N.W. 9th Avenue
Miami, FL 33136
USA
Contact: Nathan Slewett,
Chairman
TEL: (305) 547-6666
FAX: (305) 243-4403
✉mailbox@npf.med.miami.edu
Web Site:
http://www.parkinson.org/
Resources*: *n, v, br, bk, ep, sg, pp, rs, th, fe, rg

Parkinson's Disease Foundation
833 W. Washington Blvd.
Chicago, IL 60607
USA
Contact: Judy Rosner / Jeanne Lee
TEL: (312) 733-1893
FAX: (312) 733-1896
✉UPF_ITF@msn.com
Web Site: http://www.pdf. org
Resources*: *n, v, a, br, ep, sg, rs, th, fe, rg

Parkinson's Disease Foundation
710 West 168th Street 3rd floor
New York, NY 10032
USA
Contact: Robin Elliott
TEL: (800) 457-6676 or (212) 923-4700
FAX: (212) 923-4778
✉pdfcpmc@aol.co
Web Site: http://www.pdf.org
Resources*: *n, v, a, br, ep, sg, rs, th, fe, rs

PROGRESSIVE SUPRANUCLEAR PALSY

EUROPEAN

PSP Europe Association
Wappenham
Towchester
Northants NN12 8SQ UK
Contact: The Old Rectory
TEL: (44) 1327 860 299
FAX: (44) 1327 861 007
✉psp.eur@virgin.net
Web Site: http://www.pspeur.org

USA

Society for PSP, Inc.
Woodholme Medical Bldg., Ste.
#515, 1838 Greene Tree Road
Baltimore, MD 21208
USA
Contact: Ellen Pam Katz
TEL: (410) 486-3330
FAX: (410) 486-4283
✉SPSP@Erols.com
Web Site: http://www.psp.org
Resources*: *n, v, er, br, ep, sg, pp, rs, th, fe, rg

RESTLESS LEGS SYNDROME

GERMANY

Deutsche Restless Legs Vereinigung
Max Planck Institute
Munich, Germany
Contact: Claudia Trenkwalder, MD
TEL: (49) 89 30 62 2585

UK

EKBOM Support Group
18 Rodbridge Drive
Thorpe Bay
Essex SS1 3DS UK
Contact: Eileen Gill
TEL: (44) 1702 582002
✉gill@ekbom-88.demon.co.uk

USA

Restless Legs Syndrome Foundation
819 Second Street SW
Rochester, MN 55902
USA
TEL: (507) 287-6465
FAX: (507) 287-6312
✉rlsfoundation@rls.org
Web Site: http://www.rls.org
Resources*: *n, er, br, sg, rg

RETT SYNDROME

AUSTRALIA

Rett Syndrome Association of Australia
GPO Box 3497
Melbourne, Victoria 3001
Australia
Contact: Bill Callaghan, President
TEL: (61) 3 96157077
Web Site:
http://www.general.uwa.edu.au/u/hleonard/

AUSTRIA

Austrian Rett Syndrome Association
Kaiser Josef-Strasse 3
Wolkersddorf A-2120 Austria
Contact: Irmgard Wenzel
TEL: +43 2245 5084
FAX: +43 2245 5084 22
✉info@rettsyndrom.at
Web Site: http://www.rettsyndrom.at

FRANCE

Association Francaise du Syndrome Rett
41, rue Roger Bodineau
Larcay 37270 France
TEL: (33) 2 47 48 05 62
FAX: (33) 2 47 05 76 99

INTERNATIONAL ASSOCIATION

International Rett Syndrome Association
9121 Piscataway Road, Suite 2B
Clinton, MD 20735
USA
Contact: Kathy Hunter
TEL: 301-856-3334
FAX: 301-856-3336
✉khunter@rettsyndrome.org
Web Site: http://www.rettsyndrome.org

JAPAN

Japan Rett Syndrome Association
Japan
TEL: 043 238 8898
FAX: 043 238 8903

NORWAY

Norwegian Rett Syndrome Association
Apenesbakken 7
Horton 3183 Norway
Contact: Hanne Blom-Bakke
TEL: (47) 3304 6546
✉Haaso@online.no
Resources*: *n, v, br, ep, sg

UK

Rett Syndrome Association UK
113 Friern Barnet Road
London N11 3EU UK
Contact: Heidi Kurowska
TEL: (44) 20 8361 5161
FAX: (44) 20 8368 6123
✉info@rettsyndrome.org.uk
Web Site:
www.rettsyndrome.org.uk

SPASTICITY

ARGENTINA

E.M. Argentina Asociacion Civil
Uriarte 1465/69
Buenos Aires 1414 Argentina
TEL: (54) 1831 6617
FAX: (54) 1831 6786
✉emarg@dacas.com.ar

AUSTRALIA

National MS Society of Australia
34 Jackson Street
Toorak, Victoria 3142
Australia
TEL: (613) 9828 7222
FAX: (613) 9826 9054
✉public@mssociety.com.au
Web Site: http://www.msaustralia.com

The Spastic Center of New South Wales
189 Allambie Road
Alllambie Heights
NSW 2100 Australia
TEL: (61) 2 451 9022
FAX: (61) 2 451 4877

AUSTRIA

Österreichische MS Gesselischaft
Wahringer Guertel 18-20
Vienna A-1090 Austria
TEL: (43) 140 400 3121
FAX: (43) 140 400 3141

BELGIUM

Ligue Belge de la Sclerose en Plaques
173 bt 11 Avenue Plasky
Bruxelles B-1030 Belgium
TEL: (32) 2736 1638
FAX: (32) 2732 3959

BRAZIL

ABEM
Rua Demostenes 283
Sao Paulo 04614-011 Brazil
TEL: (55) 11 531 1928
FAX: (55) 11 533 0582
✉abem@abem.org.br

CANADA

Canadian Multiple Sclerosis Association
2550 Argentia Road, Suite 230
Mississauga, Ontario L5N 5R1
Canada
TEL: (888) 395-2672(CMSA)
FAX: (905) 812-3522

Ontario Federation for Cerebral Palsy
1630 Lawrence Avenue West,
Auite 104
Toronto, Ontario M6 L IC5
Canada
TEL: (416) 244-9686
FAX: (416) 244-6543

CYPRUS

Cyprus MS Association
PO Box 6749
Nicosia 1647 Cyprus
TEL: (357) 2 525053
FAX: (357) 2 524287

DENMARK

The Danish MS Society
Mosedalvej 15
Copenhagen
Valby DK-2500 Denmark
TEL: (45) 3646 3646
FAX: (45) 3646 3677

FINLAND

The Finnish MS Society
PL 15
Masku 21251 Finland
TEL: (358) 02 439 2111
FAX: (358) 02 439 2133
✉ms-liitto@msl.pp.fi
Web Site: http://www.ms-litto.fi/english.htm
***Resources:* n, v, br, bk, ep, sg, fe, rg**

FRANCE

Ligue Francaise Contre la Sclérose en Plaq.
Tour CIT - BP 68, 3 rue de l'arrivée
Paris 75015 France
TEL: (33) 1 4322 4569
FAX: (33) 1 4232 5415
Web Site: http://www.handinews.com/LFSEP

LSFEP
40 Rue Duranton
Paris 75015 France
TEL: (33) 1 5398 9880
FAX: (33) 1 5398 9888
Web Site:
http://www.lfsep.asso.fr

GERMANY

Deutsche Multiple Sklerose Gesellschaft (DMSG) Bundesverbard e.V.
Vahrenwalder Str. 205-207
Hannover 30165 Germany
TEL: (49) 5 1196 8340
FAX: (49) 5 1196 83450
Web Site: http://www.dmsg.de

GREECE

Greek MS Society
Vouliagmenis Avenue, Hellinikon 167 77
Athens, Greece
TEL: (301) 964 4166/7
FAX: (301) 964 2399

HUNGARY

MS Society of Hungary
Department of Neurology, H-8001 Szekesfehervar
Seregelyesi ul. 3
H-8001
Hungary
TEL: (36) 22 316001
FAX: (36) 22 314198

ICELAND

MS Felag Islands
Slettuvegur 5
103 Reykjavik
Simi, Iceland
Contact: Gyda Olafsdottir
TEL: (354) 568 8620
FAX: (354) 568 8688
✉msfelag@mmedia.is

INDIA

MS Society of India
c/o Motor Industries Co. Ltd., PB No 3000, Hosur Road, Adugodi
Bangalore 560 030 India
Contact: Devi Bala
TEL: (91) 80 222 1571
FAX: (91) 80 227 2628

INTERNATIONAL ASSOCIATION

International Brain Injury Association
1150 South Washington Street, Suite 210
Alexandria, VA 22314
USA
TEL: (804) 296-IBIA
FAX: (804) 296-4546
Web Site: http://www.internationalbrain.org

International CP Society
5 A Netherhall Gardens
London NW3 5RN UK
Contact: Anita Loring
TEL: (44) 207 794 9761

International Federation of MS Societies
10 Heddon Street
London W1R 7LJ UK
Contact: Richard Hamilton
TEL: (44) 207 734 9120
FAX: (44) 207 287 2587
Web Site:
http://www.ifmss.org.uk

IRELAND

MS Society of Ireland
2 Sandymount Green
Dublin 4 Ireland
TEL: (353) 1269 4599
FAX: (353) 1269 3746
✉mssoi@iol.ie

National Association for Cerebral Palsy Ltd.
Sanydmont Avenue
Dublin 4 Ireland
TEL: (353) 1 269 5355
FAX: (353) 1 269 4983

ISRAEL

Israel MS Society
75 Yehuda Halevi Street
Tel Aviv 65796 Israel
TEL: (972) 3560 9222
FAX: (972) 5 3560 9224

ITALY

Assoc. Italiana Sclerosi Multipla
Vico Chiuso Paggi 3
Genova 16128 Italy
TEL: (39) 010 27131
FAX: (39) 10 247 0226
✉aism@aism.it

JAPAN

Japan MS Society
4-1-2 Kotobuki, Taitoku
Tokyo, Japan
TEL: (81) 338 47 3504
FAX: (82) 338 42 4906

LUXEMBOURG

Ligue Luxembourgeoise de la Sclerose en Plaques
BP 1444
L-1014
Luxembourg
TEL: (352) 400 944
FAX: (352) 400 844

MEXICO

Asociacion Mexicana contra la EM
Calzada de Tlalpan 4515, Tlalpan - Toriello Guerra
Mexico D.F. 14050 Mexico
Contact: Ian Thomas, CEO
TEL: (52) 5550 9987
FAX: (52) 5616 4509
✉thomasir@mpsnet.com.mx
Web Site:
http://www.amcem.org.mx

NORWAY

Multipel Sklerose Forbundet I Norge
Sorkadalsveien 3
Oslo 3 0369 Norway
TEL: (47) 2260 4960
FAX: (47) 22256 7695

POLAND

MS Society of Poland
Al. Jerozolimskie 65/79
Warsaw 00-697 Poland
Contact: Maria Kassur
TEL: (48) 22 630 7220
FAX: (48) 22 630 7220
***Resources:* n, v, er, br, bk, ep, sg, rs, th, fe, rg**

PORTUGAL

Sociedade Portuguesa de Esclerose Multiple
Rua de Xabregas, 2 - sala 2.03
Lisboa 1900 Portugal
TEL: (351) 1 868 38 72
FAX: (351) 1 868 38 95

PUERTO RICO

Multiple Sclerosis of Puerto Rico
Villas De Parque Escorial Edif. D #903
Carolina 00987 Puerto Rico
Contact: Harry Martinez-Rivera
TEL: (787)762-4887
✉martinezharry@hotmail.com

SLOVENIA

Drustvo MS Slovenije
Maroltova ul. 14
Ljubljana 1113 Slovenia
TEL: (386) 61 168 7297
FAX: (386) 61 168 7297

SOUTH AFRICA

South African Nat. MS Society
295 Villiers Road, Walmer
Port Elizabeth 6070 South Africa
TEL: (27) 4151 2900
FAX: (27) 4151 5705
✉sanmss@jhb.lia.net

SPAIN

Asociacion Espanola de EM (AEDEM)
8 1\0xBC Centro Derecha
Madrid 28010 Spain
TEL: (34) 91448 1261
FAX: (34) 91448 1261
Web Site:
http://www.usuarios.isid.es/users/aedem

Asociacion Nacional Cerebral de Espana
Calle Comunidad de Canarias, 27
Las Rozas, Madrid 28230 Spain
Contact: Pedro Jonaquin Fernandes Navarro

SWEDEN

Neurologiskt Handikappades Riksforbund (NHR)
The Association for the Neurologically Disabled
PO Box 3284
Stockholm S-103 65 Sweden
Contact: Caroline Akerhielm
TEL: (46) 8 677 70 10
FAX: (46) 8 24 13 15
✉nhr@nhr.se
Web Site: http://www.nhr.se

SWITZERLAND

Schweizerische MS-Gesellschaft
Swiss Multiple Sclerosis Society
Brinerstrasse 1
Zurich CH-8036 Switzerland
TEL: (41) 1 466 69 99
FAX: (41) 1 466 69 90
✉info@multiplesklerose.ch
Web Site: http://www.multiplesklerose.ch

THE NETHERLANDS

Multiple Sclerose Vereniging Nederland
Bronovolaan 1d
Den Haag 2597 AX The Netherlands
TEL: (31) 70 374 7777
FAX: (31) 70 374 7770
***Resources:* n, v, er, br, bk, ep, sg, pp, th**

TURKEY

Turkiye Multipl Skleroz Dernegi
Hukukcular Sitesi No. 24121
Mecideyekoy
Istanbul 80290 Turkey
Contact: Boyokdere Caddesi
TEL: (90) 212 275 2296/7
FAX: (90) 212 275 2290

UK

HEADWAY (National Head Injuries Association, Ltd.)
7 King Edward Court, King Edward Street
Nottingham N91 1EW UK
Contact: Jan Davidson
TEL: (44) 115 912 1000
FAX: (44) 115 912 1011
***Resources:* n, bk, sg, rs, th, fe**

MS Society of Great Britain and Northern Ireland
25 Effie Road
London SW6 1EE UK
TEL: (44) 207 610 7171
FAX: (44) 207 736 9861
✉info@mssociety.org.uk
Web Site:
http://www.mssociety.org.uk

PARNET (Rescue Foundation for Brain Injured Infant)
Pigeonsford, Llangrannog
Llandysul
Ceredigion SA44 6AF
Wales, UK
Contact: Gill Gleeson
TEL: (44) 1239 652104
FAX: (44) 1239 652136
✉gill456@gn.apc.org
Web Site: http://www.babybrains.org
***Resources:* Information and support network for parents of brain injured children. Postal lending library.**

SCOPE
6 Market Rd
London N7 9PW UK
Contact: Richard Parnell
TEL: (44) 207 619 7258
FAX: (44) 207 619 7380
✉richard.parnell@scope.org.uk
Web Site:
http://www.scope.org.uk

The Stroke Association
Stroke House, Whitecross Street
London EC1Y 8JJ UK
Contact: Margaret Goose
TEL: (44) 207 566 0300
FAX: (44) 207 490 2686
Web Site:
http://www.stroke.org.uk
***Resources:* n, v, a, br, bk**

INTERNATIONAL GUIDE TO MOVEMENT DISORDER PATIENT ADVOCACY GROUPS AND FOUNDATIONS

From WE MOVE (Worldwide Education and Awareness for Movement Disorders)

USA

American Stroke Association
A Division of American Heart Association
7272 Greenville Avenue
Dallas, TX 75231
USA
TEL: (388) 4 STROKE
FAX: (800) 787-8985
✉strokeassociation@heart.org
Web Site: http://www.StrokeAssociation.org

Brain Injury Association, Inc
105 North Alfred Street
Alexandria, VA 22314
USA
Contact: Fred Krause
TEL: (800) 444-6443 or (703) 236-6000
FAX: (703) 236-6001
✉PublicRelations@biausa.org
Web Site: http://www.biausa.org
***Resources:* n, v, a, br, bk, ep, sg, rs, th, fe, rg**

Christopher Reeve Paralysis Foundation
500 Morris Avenue
Springfield, NJ 07081
USA
TEL: (800) 225-0290 or (973) 379-2690
FAX: (973) 912-9433
Web Site: http://www.apacure.com
***Resources:* n, br, fe, rg**

Multiple Sclerosis Association of America
706 Haddonfield Road
Cherry Hill, NJ 08002
USA
Contact: Susan Freund
TEL: (800) 833-4MSA(4672)
FAX: (609) 661-9797
✉msaa@msaa.com
Web Site: http://www.msfacts.org
***Resources:* n, v, er, br, bk, ep, sg, pp, rs, th, fe**

Multiple Sclerosis Foundation
6350 N. Andrews Avenue
Ft. Lauderdale, FL 33309
USA
TEL: (800) 441-7055 or (954) 776-6805
FAX: (954) 938-8708
✉support@msfacts.org
Web Site: http://www.msfacts.org
***Resources:* n, v, a, br, bk, sg, pp, rs, th, fe, rg**

National Multiple Sclerosis Society
733 3rd Avenue, 6th Floor
New York, NY 10017-3288
USA
TEL: (800) FIGHT MS (344-4867) or (212) 986-3240
FAX: (212) 986-7981
✉info@nmss.org
***Resources:* n, v, br, bk, ep, sg, rs, rg**

National Spinal Cord Injury Association
6701 Democracy Boulevard
Bethesda, MD 20817
USA
Contact: Diane Barry
TEL: (800) 962-9629 or (301) 588-6959
FAX: (301) 588-9414
Web Site: http://www.spinalcord.org
***Resources:* br, bk, ep, pp**

National Stroke Association
96 Inverness Drive East, Suite 1
Englewood, CO 80111-5112
USA
TEL: (800) STROKES or (303) 649-9259
FAX: (303) 771-1887
Web Site: http://www.stroke.org
***Resources:* n, br, sg, ep, rs**

Stroke Club International
805 12th Street
Galveston, TX 77550
USA
Contact: Ellis Williamson
TEL: (409) 762-1022
✉strokeclub@aol.com
***Resources:* n, er, ep**

United Cerebral Palsy Associations
1660 'L' Street NW, Suite 700
Washington, DC 20036
USA
Contact: Michael Morris
TEL: (800) USA 5UCP or (202) 842-1226
FAX: (202) 842-3519
Web Site: http://www.ucpa.org
***Resources:* n, br, ep, sg**

ZIMBABWE

MS Society of Zimbabwe
PO Box 1234
Belvedere, Harare
Zimbabwe
TEL: (263) 4 740472
FAX: (263) 740472

TARDIVE DYSKINESIA/DYSTONIA

USA

Tardive Dyskinesia/Tardive Dystonia National Assoc.
4244 University Way NE,
PO Box 45732
Seattle, WA 98145-0732
USA
Contact: S. K. Kjaer
TEL: (206) 522-3166

TICS/TOURETTE'S SYNDROME

ARGENTINA

Tourette Syndrome Association of Argentina
Segurola 483, V.Sarmiento (1706)
Buenos Aires
Argentina
Contact: Stella Ortiz

AUSTRALIA

Tourette Syndrome Association of Australia
PO Box 1173
Maroubra, New South Wales 2035
Australia
Contact: Debbie Redelman
TEL: (61) 2 9382 3726
FAX: (61) 2 9382 3764
Email: info@tourette.org.au
Web Site: http://www.tourette.org.au
***Resources:* n, v, a, er, br, bk, ep, sg, pp, rs, th, fe**

TSA of Queensland
20 Balfour Street
Newfarm 4007 Australia
TEL: (61) 7 3358 4988

TSA of South Australia
23a King William Street
Unley 5061 Australia
TEL: (61) 8 8357 8909
FAX: (61) 8 8357 8876
✉nrc@camtech.net.au

TSA of Victoria, Inc.
34 Jackson Street
Toorak 3142 Australia
Contact: Tim Morrissey
TEL: (61) 3 9828 7218
FAX: (61) 3 9826 9054
✉tourettes@mssociety.com.au
Web Site: http://www.devolution.com.au/tourette

Western Australia TS Organisation
320 Rokeby Road
Sabiaco 6008 Australia
TEL: (61) 9388 3486
FAX: (61) 9382 1149

AUSTRIA

Öestereichische Tourette Geselschaft
Wien Universitat Hospital vor Psykiatrie, Wahringergutrel 18-20
Wien A 1090 Austria
Contact: Maria Stamenkovic
TEL: (43)140 400 3526
FAX: (43) 140 400 3560

BELGIUM

Vlaamse Vereniging Gilles de la Tourette
Nauwelaertstraat 7
Wynegem 2210 Belgium
Contact: Vera Casier Cassimon Jozet
TEL: (32) 33 54 3669
FAX: (32) 35 53 6791
✉vera@glo.be
***Resources:* n, v, er, br, bk, ep, sg, pp, rs, th, fe**

BRAZIL

Associaco de Pacientes com Sindrome de Tourette Tiques e transformos Obsessivo-compulsivo (ASTOC)
R. Bras Cardoso 201
Sao Paulo, Brazil
TEL: (55) 11 822 0023
FAX: (55) 11 822 0023

CANADA

Tourette Syndrome Foundation of Canada
206-194 Jarvis Street
Toronto, Ontario M5B 2B7
Canada
Contact: Rosie Wartecker
TEL: (416) 861-8398 or (800) 361-3120
FAX: (416) 861-2472
✉tsfc.org@sympatico.ca
Web Site: http://www.tourette.ca
***Resources:* n, v, er, br, bk, ep, sg, th, fe, rg**

DENMARK

Dansk Tourette Forening
Sollerodvej 76
Holte DK 2840 Denmark
Contact: Kjeld Christensen
TEL: (45) 45 80 07 53
FAX: (45) 45 80 32 16
✉tdc@post8.tele.de
Web Site: http://www.tourette.dk

FINLAND

Suomen Tourette Yhdistys
Finnish Tourette Association
Contact: Mika Marjalaakso
✉mika.marjalaakso@tourette.fi

GERMANY

Tourette-Gesellschaft Deutschland e.V.
Von Siebold Str. 5
Gottingen 37015 Germany
Contact: Tourette Gesellschaft Deutschland e.V. - c/o Prof. Dr. A. Rothen
TEL: (49) 551 396727
FAX: (49) 551 398120
✉info@tourette.de
Web Site: http://www.tourette.de
***Resources:* n, v, er, br, bk, ep, sg**

ICELAND

Tourette Samtokin a Islandi
Postholf 3128
Reykjavik 123 Iceland
Contact: Eliz. Magrusdottir
TEL: (354) 588 8581
FAX: (354) 551 4580
✉emagn@islandia.is
***Resources:* n, v, er, br, ep, sg, th**

INTERNATIONAL ASSOCIATION

Tourette Syndrome Global Awareness Program
Munkerudasen 33
Oslo N-1165 Norway
Contact: Christian Melbye
FAX: (47) 22 28 67 52
✉melbye@intertourette.com
Web Site: http://www.intertourette.com

IRELAND

Tourette Syndrome Association of Ireland
29 Granville Road
Dun Laoghair
Dublin, Ireland
Contact: Una Finucane
TEL: (353) 1 623 0500
FAX: (353) 1 623 0500

ISRAEL

Yirgoon Syndrome Tourette Israel (ESTI)
PO Box 7018
Ramat Gan 52170 Israel
Contact: Anat Imber
TEL: (03) 9012956
***Resources:* n,er,br,sg,th**

NEW ZEALAND

TSA of New Zealand
146 Weymouth Road, Manurowa
South Auckland, New Zealand
Contact: Carol Bridle

NORWAY

Norsk Tourette Forening
Brolandsveien 19 B
Oslo N-0980 Norway
Contact: Tom A. Wulff, President
TEL: (47) 2221 6506
FAX: (47) 2210 9921

PERU

Asociaocion Sindrome de Tourette del Peru
Las Golondras no. 390
Lima 27 Peru
Contact: Luisa Fernanda L. Romana

POLAND

Polskie Stowarzyszenie Syndrom Tourette'a
c/o Osrodek Informacij TOPOS
38/40 ul.Dulga
Warsaw 00-238 Poland
Contact: Ewa Boguszewska
TEL: (48) 22 831 22 12 (Tuesdays from 17:00 - 18:30hrs)
FAX: (48) 22 831 47 12
✉aboguszewski@poczta.onet.pl
***Resources:* br, er, rs, sg, th**

SPAIN

Asociacion Espanola para Tics y Tourette
Gran Via de les Corts Catalanes, 562 pral. 2a
Barcelona 08011 Spain
TEL: (34) 451 5550
***Resources:* n, v, a, er, ba, br, ep, sg, pp, rs, th, fe**

SWEDEN

Svensk Tourette Forening
St Johannesgatan 28
Uppsala S 752 33 Sweden
TEL: (46) 18 56 09 04
FAX: (46) 18 56 09 01
✉info@tourette.se

KEY TO SERVICES

n	newsletter
v	video tape
a	audio tape
er	educator's resource materials
br	brochure, fact sheet
bk	book
ep	educational program
sg	support group meeting
pp	"Pen Pal" network
rs	referral service
th	telephone "hotline"
fe	fundraising event
rg	research grant

SWITZERLAND

Tourette Gesellschaft Schweiz Burozentrum
Gibraltarstrasse 34, Postfach 7147
600 Luzern 7
Switzerland
TEL: (41) 1 760 0265

THE NETHERLANDS

Stiching Gilles de la tourette
Post bus 925
Rhoon 3160 AC The Netherlands
TEL: (31) 10 501 3043
FAX: (31) 10 591 5278

UK

Tourette Syndrome (UK) Association
1st Floor Offices, Old Bank Chambers, London Road,
Crowborough
East Sussex TN6 2TT UK
TEL: (44) 1892 669 151
FAX: (44) 1892 663 649
✉101667.3131@compuserve.com
Web Site: http://www.tsa.org.uk

USA

Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
Bayside, NY 11361
USA
Contact: Jennifer Cammon
TEL: (718) 224-2999 / (800) 237-0717
FAX: (718) 279-9596
Email: ts@tsa-usa.org
Web Site: http://www.tsa-usa.org
***Resources**: n, v, a, er, br, ep, sg, rs, le, rg*

TREMOR

INTERNATIONAL ASSOCIATION

International Tremor Foundation
7046 West 105th Street
Overland Park, KS 66212-1803
USA
Contact: Catherine Rice
TEL: (888) 387-3667
FAX: (913) 341-1296
✉Staff@essentialtremor.org
Web Site: http://www.essentialtremor.org
***Resources**: n, br, ep, rs, pp, le, rg*

International Tremor Foundation
Disablement Services Center,
Harold Wood Hospital
Rumford
Essex RM3 OBE UK
Contact: Karen Walsh
TEL: (44) 1708 386399
FAX: (44) 1708 378032
***Resources**: n, ls, pp, rs, th*

WILSON DISEASE

USA

Wilson's Disease Association
4 Navajo Drive
Brookfield, CT 06810-3124
USA
Contact: H. Ascher Sellner, MD
TEL: (800) 399-0266 or (203) 775-9666
FAX: (203) 743-6196
✉ahasellner@worldnet.att.net
Web Site: http://www.wilsonsdisease.org
***Resources**: n, a, br, sg, rs, th*

NOTES:

FREEDOM
FREEDOM Concepts Inc.
"MAKING MOBILITY A REALITY"™
REAR STEERING
TANDEM
JOURNEY
CONCEPTS INC
www.freedomconcepts.com

HANDCRAFTED WITH PRIDE, QUALITY AND INGENUITY AT A REASONABLE PRICE

FREEDOM CONCEPTS INC.
45117 RPO REGENT, WINNIPEG, MB R2C 5C7
PHONE: 1-800-661-9915 FAX: 204-654-1149
EMAIL: MOBILITY@FREEDOMCONCEPTS.COM

Circle #59 or visit www.eparent.com/adinfo

STATE DIRECTORS OF SPECIAL EDUCATION

Every state has a state education agency that is responsible for general supervision of the state's special education services for children and young adults with disabilities. Within each agency, one individual has the primary responsibility of overseeing these services. Usually, this person is called the State Director of Special Education. This individual—or his or her staff—can direct parents to appropriate local resources; is knowledgeable about the state's procedural safeguard system (the system for handling complaints, mediation, and due process procedures); and can offer other assistance as needed.

The listings in this directory were provided by the National Association of State Directors of Special Education [NASDSE, 1800 Diagonal Rd., Alexandria, VA 22314; (703) 519-3800 (voice); (703) 519-7008 (TDD); (703) 519-3808 (fax)], and are current as of November 2001.

ALABAMA

MR. MABREY WHETSTONE
ALABAMA DEPARTMENT
OF EDUCATION
SPECIAL EDUCATION SERVICES
BOX 302101
GORDON PERSONS BUILDING
MONTGOMERY, AL 36130-2101
(334) 242-8114
(334) 242-9192 (FAX)

ALASKA

MR. GREG MALONEY
STATE DIRECTOR OF
SPECIAL EDUCATION
OFFICE OF SPECIAL AND
SUPPLEMENTAL SVCS
ALASKA DEPARTMENT
OF EDUCATION
801 W TENTH STREET, SUITE 200
JUNEAU, AK 99801-1894
(907) 465-2972
(907) 465-2806 (FAX)

ARIZONA

DR. LYNN BUSENBARK
EXCEPTIONAL STUDENT
SERVICES
ARIZONA DEPARTMENT
OF EDUCATION
1535 W. JEFFERSON
PHOENIX, AZ 85007-3280
(602) 542-4831
(602) 542-5404 (FAX)

MR. STEVE MISHLOVE
(602) 542-3084
(602) 542-5404 (FAX)

JULIE GASAWAY
DIRECTOR OF
SPECIAL PROJECTS
EXCEPTIONAL STUDENT
SERVICES
ARIZONA DEPARTMENT
OF EDUCATION
1535 WEST JEFFERSON
PHOENIX, AZ 85007
(602) 364-4023
(602) 542-5404 (FAX)

ARKANSAS

MARCIA HARDING
ACTING DIRECTOR
FOR SPECIAL EDUCATION
ROOM 105-C, DEPT.
OF EDUCATION BUILDING
#4 STATE CAPITOL MALL
LITTLE ROCK, AR 72201-1071
(501) 682-4221
(501) 682-5159 (FAX)

AMERICAN SAMOA

MS. JANE FRENCH
ASSISTANT DIRECTOR FOR
SPECIAL EDUCATION
AMERICAN SAMOA
DEPARTMENT OF EDUCATION
PAGO PAGO, AS 96799
011684/633-1323
011684/633-7707 (FAX)

BUREAU OF INDIAN AFFAIRS

DR. SHERRY ALLISON
CHIEF BRANCH OF EXCEPTIONAL EDUCATION
BUREAU OF INDIAN AFFAIRS
500 GOLD STREET
ALBUQUERQUE, NM 87103
(505) 248-7553
(505) 248-7546 (FAX)

CALIFORNIA

DR. ALICE PARKER
STATE DIRECTOR
SPECIAL EDUCATION DIVISION
CALIFORNIA DEPARTMENT
OF EDUCATION
515 L STREET, #270
SACRAMENTO, CA 95814
(916) 445-4602
(916) 327-3706 (FAX)

COLORADO

MS. LORRIE HARKNESS
STATE DIRECTOR OF
SPECIAL EDUCATION
SPECIAL ED. SERVICES UNIT
COLORADO DEPARTMENT
OF EDUCATION
201 E COLFAX AVENUE
DENVER, CO 80203
(303) 866-6695
(303) 866-6811 (FAX)

COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS

ANN QUICK
SPECIAL EDUCATION
PROGRAMS
COMMONWEALTH OF THE
NORTHERN MARIANA ISLANDS
PUBLIC SCHOOL SYSTEM
P. O. BOX 1370 CK
SAIPAN, CNMI 96950
(670) 664-3754
(670) 664-3996 (FAX)

CONNECTICUT

MR. GEORGE DOWALIBY
DIRECTOR
DIVISION OF EDUCATIONAL
PROGRAMS & SVCS
BUREAU OF SPECIAL
EDUCATION & PUPIL SVCS.
CONNECTICUT STATE
DEPARTMENT OF ED
25 INDUSTRIAL PARK ROAD
MIDDLETOWN, CT 06457
(860) 807-2025
(860) 807-2047 (FAX)

DELAWARE

DR. MARTHA BROOKS
DIRECTOR
EXCEPTIONAL CHILDREN
& EARLY
CHILDHOOD GROUP
DELAWARE DEPARTMENT
OF EDUCATION
P. O. BOX 1402
DOVER, DE 19903-1402
(302) 739-5471
(302) 739-2388 (FAX)

DEPARTMENT OF DEFENSE

LORIE SEBESTYEN
ACTING DIRECTOR
OFFICE OF DEPENDENTS
EDUCATION
4040 FAIRFAX DRIVE
ARLINGTON, VA 22203
(703) 696-4493
(703) 696-8924 (FAX)

DISTRICT OF COLUMBIA

MS. ANNE GAY
ASSOCIATE SUPERINTENDENT
FOR SPECIAL EDUCATION
DC PUBLIC SCHOOLS
825 N. CAPITOL STREET, NE
6TH FLOOR
WASHINGTON, DC 20003
(202) 442-5511
(202) 442-5518 (FAX)

FEDERATED STATES OF MICRONESIA

MR. MAKIR M. KELLER
EXECUTIVE DIRECTOR
SPECIAL EDUCATION
FEDERATED STATES OF
MICRONESIA NATIONAL
GOVERNMENT
KOLONIA, POHNPEI, FSM 96941
(691) 320-2609
(691) 320-5500 (FAX)

FLORIDA

MS. SHAN GOFF
BUREAU CHIEF
BUREAU OF INSTRUCTIONAL
SUPPORT & COMMUNITY
SERVICES
FLORIDA DEPARTMENT
OF EDUCATION
325 W. GAINES STREET;
SUITE 614
TALLAHASSEE, FL 32399-0400
(850) 488-1570
(850) 921-8246 (FAX)

GEORGIA

MR. PHILIP PICKENS
DIVISION FOR EXCEPTIONAL
STUDENTS
GEORGIA DEPARTMENT OF
EDUCATION
1870 TWIN TOWERS EAST
205 BUTLER STREET
ATLANTA, GA 33334-5040
(404) 656-3963
(404) 651-6457 (FAX)

GUAM

MR. VINCE LEON GUERRERO
ASSOCIATE SUPERINTENDENT
DIVISION OF SPECIAL
EDUCATION
GUAM DEPARTMENT
OF EDUCATION
P. O. BOX DE
HAGATNA, GU 96932
(671) 475-0549
(671) 475-0562 (FAX)

HAWAII

MS. DEBRA FARMER
ACTING DIRECTOR
STATE SPECIAL EDUCATION
SECTION
HAWAII DEPARTMENT
OF EDUCATION
3430 LEAHI AVENUE
HONOLULU, HI 96815
(808) 733-4990
(808) 733-4841 (FAX)

IDAHO

JANA JONES
SPECIAL EDUCATION SECTION
STATE DEPARTMENT OF ED.
P. O. BOX 83720
BOISE, ID 83720-0027
(208) 332-6917
(208) 334-4664 (FAX)

ILLINOIS

DR. CHRISOPHER KOCH
DEPUTY SUPERINTENDENT FOR
SPECIAL ED.
ILLINOIS STATE BOARD OF
EDUCATION
100 N. FIRST STREET, MAIL
CODE N-243
SPRINGFIELD, IL 62777-0001
(217) 524-4096
(217) 524-6125 (FAX)

INDIANA

MR. ROBERT A. MARRA
DIRECTOR
DIVISION OF SPECIAL EDUCATION
INDIANA DEPT. OF EDUCATION
STATE HOUSE, ROOM 229
INDIANAPOLIS, IN 46204-2798
(317) 232-0570
(317) 232-0589 (FAX)

IOWA

DR. BRENDA OAS
BUREAU CHIEF
BUREAU OF CHILDREN, FAMILY
& COMMUNITY
SERVICES
IOWA DEPARTMENT OF PUBLIC
INSTRUCTION
GRIMES STATE OFFICE BUILDING
DES MOINES, IA 50319-0146
(515) 281-4030
(515) 242-6019 (FAX)

KANSAS

DR. BRUCE PASSMAN
STATE DIRECTOR, SPECIAL
EDUCATION
KANSAS STATE DEPARTMENT OF
EDUCATION
STUDENT SUPPORT SERVICES
120 SE 10TH AVENUE
TOPEKA, KS 66612-1182
(785) 291-3097
(785) 296-6715 (FAX)

KENTUCKY

MR. MIKE ARMSTRONG
STATE DIRECTOR
DIVISION OF EXCEPTIONAL
CHILDREN SERVICES
KENTUCKY DEPARTMENT OF
EDUCATION
500 MERO STREET, ROOM 805
FRANKFORT, KY 40601
(502) 564-4970
(502) 564-6721 (FAX)

LOUISIANA

MS. VIRGINIA BERIDON
DIRECTOR
DIVISION OF SPECIAL POPULATIONS
LOUISIANA DEPARTMENT OF
EDUCATION
P. O. BOX 94064, 9TH FLOOR
BATON ROUGE, LA 70801-9064
(225) 342-3633
(225) 342-5880 (FAX)

MAINE

MR. DAVID STOCKFORD
DIRECTOR
SPECIAL SERVICES
MAINE DEPARTMENT
OF EDUCATION
STATION #23
AUGUSTA, ME 04333
(207) 624-6650
(207) 624-6651 (FAX)

MARYLAND

MS. CAROL ANN BAGLIN
ASSISTANT STATE
SUPERINTENDENT
DIVISION OF SPECIAL
EDUCATION
MARYLAND STATE DEPARTMENT
OF EDUCATION
200 WEST BALTIMORE STREET
BALTIMORE, MD 21201-2595
(410) 767-0238
(410) 333-8165 (FAX)

MASSACHUSETTS

MS. MARCIA MITTNACHT
STATE DIRECTOR
FOR SPECIAL EDUCATION
EXECUTIVE DIRECTOR FOR ED.
IMPROVEMENT
MASSACHUSETTS
DEPARTMENT OF EDUCATION
350 MAIN STREET
MALDEN, MA 02148-5023
(781) 338-3300, X3388
(781) 338-3396 (FAX)

MICHIGAN

DR. JACQUELYN THOMPSON
DIRECTOR
MICHIGAN DEPARTMENT
OF EDUCATION
P. O. BOX 30008
608 WEST ALLEGAN STREET
LANSING, MI 48909-7508
(517) 373-9433
(517) 373-7504 (FAX)

MINNESOTA

DR. NORENA HALE
DIVISION OF SPECIAL
EDUCATION
DEPARTMENT OF CHILDREN,
FAMILIES & LEARNING
1500 HIGHWAY 36 WEST
ROSEVILLE, MN 55113-4266
(651) 582-8289
(651) 582-8729 (FAX)

MISSISSIPPI

PAULETTE WHITE
BUREAU DIRECTOR
BUREAU OF SPECIAL SERVICES
STATE DEPARTMENT
OF EDUCATION
P. O. BOX 771
359 NORTH WEST STREET
JACKSON, MS 39205-0771
(601) 359-3490
(601) 359-2198 (FAX)

MISSOURI

MS. MELODIE FRIEDEBACH
DIRECTOR
DIVISION OF SPECIAL
EDUCATION
DEPARTMENT OF ELEMENTARY
& SPECIAL ED
P.O. BOX 480
JEFFERSON CITY, MO
65102-0480
(573) 751-2965
(573) 526-4404 (FAX)

MONTANA

MR. ROBERT RUNKEL
DIRECTOR
DIVISION OF SPECIAL
EDUCATION
OFFICE OF PUBLIC
INSTRUCTION
P. O. BOX 202501
HELENA, MT 59620-2501
(406) 444-4429
(406) 444-3924 (FAX)

NEBRASKA

MR. GARY SHERMAN
DIRECTOR
SPECIAL POPULATIONS OFFICE
NEBRASKA DEPARTMENT
OF EDUCATION
301 CENTENNIAL MALL SOUTH
P. O. BOX 94987
LINCOLN, NE 68509-4987
(402) 471-2471
(402) 471-5022 (FAX)

NEVADA

MS. GLORIA DOPF
DIRECTOR
EDUCATIONAL EQUITY
NEVADA DEPARTMENT
OF EDUCATION
700 E. FIFTH STREET, SUITE 113
CARSON CITY, NV 89710-5096
(775) 687-9171
(775) 687-9123 (FAX)

NEW HAMPSHIRE

DR. MARY J. FORD
DIRECTOR
DIVISION OF INSTRUCTION
NEW HAMPSHIRE DEPARTMENT
OF EDUCATION
101 PLEASANT STREET
CONCORD, NH 03301
(603) 271-6693
(603) 271-1953 (FAX)

NEW JERSEY

MS. BARBARA GANTWERK
DIRECTOR
OFFICE OF SPECIAL EDUCATION
PROGRAMS
NEW JERSEY DEPARTMENT
OF EDUCATION
P. O. BOX 500
TRENTON, NJ 08625-0500
(609) 633-6833
(609) 984-8422 (FAX)

NEW MEXICO

BONNIE ANDERSON
INTERIM DIRECTOR
STATE DIRECTOR OF
SPECIAL EDUCATION
STATE DEPARTMENT
OF EDUCATION
300 DON GASPAR AVENUE
SANTA FE, NM 87501-2786
(505) 827-6798
(505) 827-6791 (FAX)

NEW YORK

LAWRENCE GLOECKLER
OFFICE FOR SPECIAL
EDUCATION SERVICES
NEW YORK STATE
EDUCATION DEPARTMENT
ONE COMMERCE PLAZA,
ROOM 1606
ALBANY, NY 12234-0001
(518) 474-2714
(518) 474-8802 (FAX)

NORTH CAROLINA

MR. LOWELL HARRIS
DIRECTOR
EXCEPTIONAL CHILDREN
DIVISION
NC DEPARTMENT
OF PUBLIC INSTRUCTION
301 N. WILMINGTON STREET
RALEIGH, NC 27601-2825
(919) 807-3969
(919) 807-3243 (FAX)

NORTH DAKOTA

MR. ROBERT RUTTEN
DIRECTOR
SPECIAL EDUCATION
DEPARTMENT OF PUBLIC
INSTRUCTION
600 E. BOULEVARD
BISMARCK, ND 58505-0440
(701) 328-2277
(701) 328-4149 (FAX)

OHIO

MR. ED KAPEL
INTERIM DIRECTOR
OFFICE FOR EXCEPTIONAL
CHILDREN (2ND FLOOR)
OHIO DEPARTMENT
OF EDUCATION
25 SOUTH FRONT STREET
COLUMBUS, OH 43215-4104
(614) 466-2650
(614) 728-1097 (FAX)

OKLAHOMA

MS. DARLA GRIFFIN/JOHN CORPOLONGO
EXECUTIVE DIRECTOR/
ASST. SUPERINTENDENT
SPECIAL EDUCATION SERVICES
STATE DEPARTMENT
OF EDUCATION
2500 N. LINCOLN BOULEVARD
OKLAHOMA CITY,
OK 73105-4599
(405) 521-4868
(405) 522-2066 (FAX)

OREGON

MR. STEVEN B. JOHNSON
ASSOCIATE SUPERINTENDENT
OFFICE OF SPECIAL EDUCATION
OREGON DEPARTMENT
OF EDUCATION
255 CAPITOL STREET, NE
SALEM, OR 97301-0203
(503) 378-3600 X2329
(503) 373-7968 (FAX)

PALAU

MR. EVANS IMETENGEL
COORDINATOR
REPUBLIC OF PALAU
SPECIAL EDUCATION
P. O. BOX 189
KOROR, PALAU PW 96940
(680) 488-2568
(680) 488-5298
(680) 488-5808 (FAX)

PENNSYLVANIA

MS. FRAN WARKOMSKI
DIRECTOR
BUREAU OF SPECIAL
EDUCATION
PENNSYLVANIA DEPARTMENT
OF EDUCATION
333 MARKET STREET,
7TH FLOOR
HARRISBURG, PA 17126-0333
(717) 783-6913
(717) 783-6139 (FAX)

PUERTO RICO

MS. LICELY E. FALCON DEL TORO
ASSISTANT SECRETARIAT OF
SPECIAL EDUCATION
PUERTO RICO DEPARTMENT
OF EDUCATION
P.O. BOX 190759
SAN JUAN, PR 00919-0759
(787) 753-7981
(787) 753-0015 (FAX)

REPUBLIC OF THE MARSHALL ISLANDS

MR. KANCHI HOSIA
SPECIAL EDUCATION DIRECTOR
REPUBLIC OF THE MARSHALL
ISLANDS MINISTRY
OF EDUCATION
P.O. BOX 3179
MAJURO, MH 96960
011692/625-6032
011692/625-3861 (FAX)

RHODE ISLAND

THOMAS DIPAOLA
DIRECTOR
OFFICE OF SPECIAL NEEDS
RHODE ISLAND DEPARTMENT
OF EDUCATION
255 WESTMINSTER STREET
PROVIDENCE, RI 02903
(401) 222-3505 X 2301
(401) 222-6030 (FAX)

SOUTH CAROLINA

SUSAN DURANT
OFFICE OF PROGRAMS FOR
EXCEPTIONAL CHILDREN
STATE DEPARTMENT
OF EDUCATION
RUTLEDGE BUILDING,
ROOM 505
1429 SENATE
COLUMBIA, SC 29201
(803) 734-8806
(803) 734-4824 (FAX)

SOUTH DAKOTA

MS. DEBORAH BARNETT
DIRECTOR
OFFICE OF SPECIAL EDUCATION
DEPARTMENT OF EDUCATION
& CULTURAL AFFAIRS
700 GOVERNORS DRIVE
PIERRE, SD 57501-2291
(605) 773-3678
(605) 773-3782 (FAX)

TENNESSEE

MR. JOSEPH FISHER
EXECUTIVE DIRECTOR
DIVISION OF SPECIAL
EDUCATION
TENNESSEE DEPARTMENT
OF EDUCATION
5TH FLOOR, ANDREW
JOHNSON TOWER
710 JAMES ROBERTSON
PARKWAY
NASHVILLE, TN 37243-0380
(615) 741-2851
(615) 532-9412 (FAX)

TEXAS

MR. EUGENE LENZ
SENIOR DIRECTOR
SPECIAL EDUCATION UNIT
TEXAS EDUCATION AGENCY
W.B. TRAVIS BUILDING,
ROOM 6-127
1701 N. CONGRESS AVENUE
AUSTIN, TX 78701-1494
(512) 463-9414
(512) 463-9434 (FAX)

UTAH

DR. MAE TAYLOR
DIRECTOR
AT-RISK & SPECIAL
EDUCATION SERVICES
SPECIAL EDUCATION
SERVICES UNIT
UTAH STATE OFFICE
OF EDUCATION
250 EAST 500 SOUTH
SALT LAKE CITY, UT 84111-3204
(801) 538-7711
(801) 538-7991 (FAX)

VERMONT

MR. DENNIS KANE
DIRECTOR
FAMILY & EDUCATIONAL
SUPPORT TEAM
VERMONT DEPARTMENT
OF EDUCATION
120 STATE STREET
MONTPELIER, VT 05620-2501
(802) 828-5118
(802) 828-3140 (FAX)

VIRGINIA

MR. DOUGLAS COX
DIRECTOR
OFFICE OF SPECIAL EDUCATION
& STUDENT SVCS.
VIRGINIA DEPARTMENT
OF EDUCATION
P. O. BOX 2120
RICHMOND, VA 23216-2120
(804) 225-3252
(804) 371-8796 (FAX)

US VIRGIN ISLANDS

MS. BELINDA WEST-O'NEAL
ACTING DIRECTOR,
SPECIAL EDUCATION
U. S. VIRGIN ISLANDS DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL
EDUCATION SERVICES
P.O. BOX 44-46 KONGENS GADE
CHARLOTTE AMALIE
ST. THOMAS, USVI 100802
(340) 776-5802
(340) 774-0817 (FAX)

WASHINGTON

DR. DOUGLAS GILL
STATE DIRECTOR
SPECIAL EDUCATION SECTION
SUPERINTENDENT OF
PUBLIC INSTRUCTION
OLD CAPITOL BUILDING
OLYMPIA, WA 98504-0001
(360) 753-6733
(360) 586-0247 (FAX)

WEST VIRGINIA

DR. DEE BODKINS
DIRECTOR
OFFICE OF SPECIAL EDUCATION
WEST VIRGINIA DEPARTMENT
OF EDUCATION
BLDG. 6, ROOM B-304,
CAPITOL COMPLEX
1900 KANAWHA BOULEVARD
CHARLESTON, WV 25305
(304) 558-2696
(304) 558-3741 (FAX)

WISCONSIN

DR. STEPHANIE PETSKA
STATE DIRECTOR
SPECIAL EDUCATION DIVISION
DEPARTMENT OF PUBLIC
INSTRUCTION
P. O. BOX 7841
MADISON, WI 53707-7841
(608) 266-1781
(608) 267-3746 (FAX)

WYOMING

MS. REBECCA WALK
SPECIAL EDUCATION UNIT
WYOMING DEPARTMENT
OF EDUCATION
HATHAWAY BUILDING,
2ND FLOOR
2300 CAPITOL AVENUE
CHEYENNE, WY 82002-0050
(307) 777-7417
(307) 777-6234 (FAX)

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C.
& Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at
www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #84 or visit www.eparent.com/adinfo

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

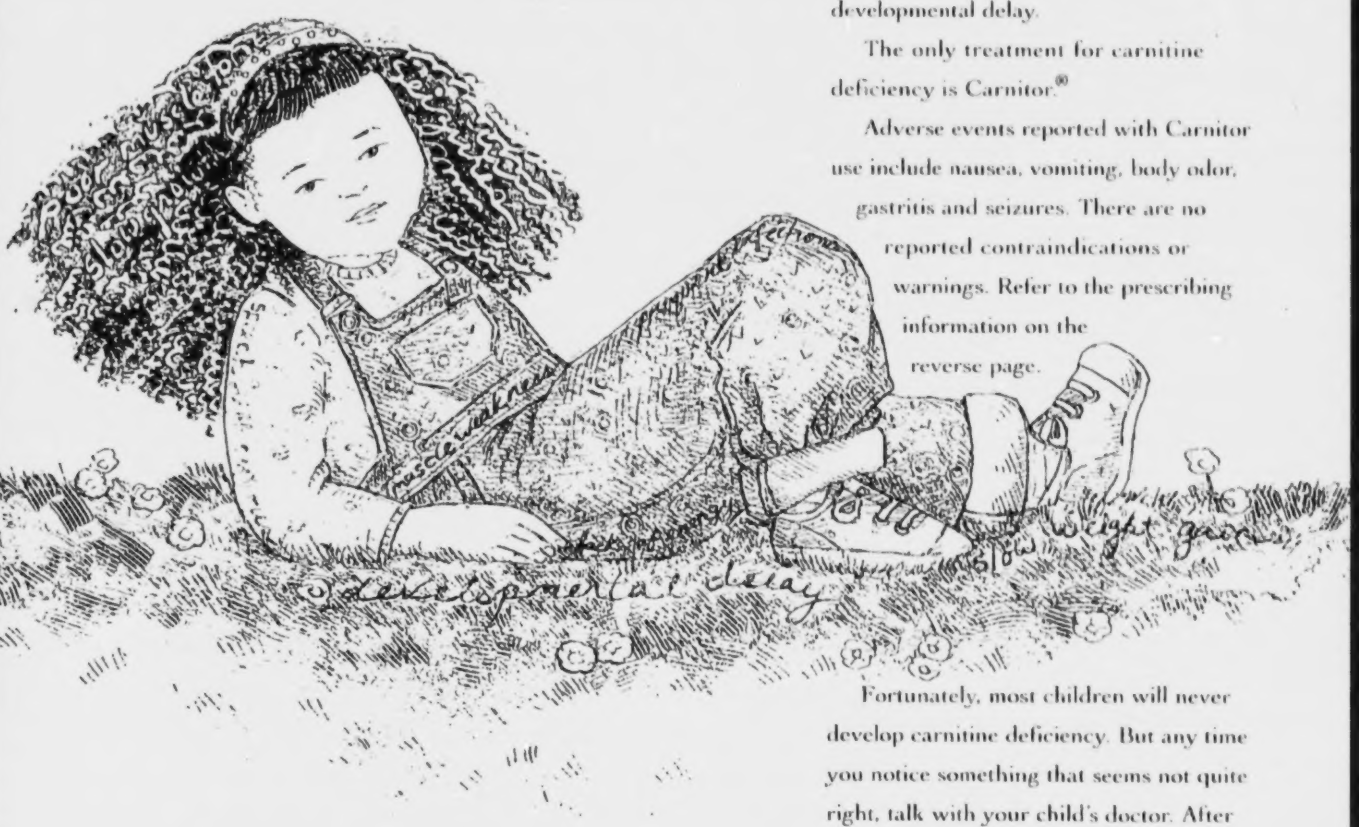
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor® levocarnitine
Tablets 330mg • Oral Solution 1g/10ml

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Circle #116 or visit www.eparent.com/adinfo

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria, II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

Imagine...

all of your other
choices could be this simple

MOTOR COMPANY, INC
LIBERTY

Introducing a

zero maintenance

conversion van with wheelchair access

Starting Under

$20,000 US

(Including vehicle and modification)

1996-2002 Windstar Models Available
(All vans come with brand new conversions)
Professionally trained staff ready to help you
The rear-entry design provides for the safest and most reliable wheelchair accessible minivan on the market.
The Liberty Motor Co modified Ford Windstar looks and drives like a standard minivan, offering a quiet, comfortable ride.
Money Back Guarantee

BEST COPY AVAILABLE

Circle #83 or visit www.eparent.com/adinfo

1 (888) 578-8886 www.libertymotorco.com

NO APOLOGIES FOR RITALIN

No Apologies For Ritalin ◦ By Vidya Bhushan Gupta, MD ◦ EP8012AD- $19.95

Despite its name, No Apologies for Ritalin is aimed at educating parents of children with ADD by presenting all the treatments available for the disorder.

The first half of the book is a look at what ADD is: the medical aspects, how it is diagnosed, and what causes it. Anecdotes of children diagnosed with the disorder and a discussion of how doctors arrive at their diagnoses begin the book. Issues that parents must deal with, such as understanding and coming to grips with the diagnosis of ADD, whether ADD is a product of bad parenting style, ADD's occurrence with other disorders, and who is most at risk are discussed in this section as well.

Section 2 presents the pros and cons of all treatment options, both conventional and alternative, including non-drug therapies such as psychotherapy and behavior modification. The author, Vidya Bhushan Gupta, MD, MPH, FAAP, writes in his Foreword, "I have discussed the controversy surrounding the use of Ritalin and tried to dispel myths surrounding ADD and Ritalin: 'ADD is not a disease; it is simply a difference of temperament;' 'ADD is due to poor parenting;' 'Ritalin is a mind-altering drug like speed;' 'Don't give Ritalin to your children because they will get hooked on it.'" He explains that his purpose for writing the book is so that "parents of children with ADD will not blame themselves for their child's predicament and will be able to use all the available treatments, including Ritalin, without guilt."

The book offers insights into other issues regarding ADD as well, including: who should treat the disorder and what the goals of that treatment should be; suggestions for parents on dealing with their child's ADD; whether children grow out of their ADD; and how to de-emphasize the negative labels of the disorder by recognizing and building on the strengths of children diagnosed with it.

Patient Persistence ◦ By Adele M. Gill ◦ EP8004GN-$19.95

Patient Persistence celebrates the ability of people to overcome obstacles to achieve their goals. Author Adele Gill invited individuals from every background to tell their stories of "hope, courage, hard work, and endurance related to health, disability, relationships, family, ministry, career, accomplishment and challenge."

Ms. Gill is a certified disability analyst/fellow with the American Board of Disability Analysts, and an advocate of inspirational/motivational self-help. She writes, "Patience and persistence are qualities that are vital to the discovery of our finest, God-given gift; the resilient 'Indelible Human Spirit.' These innate qualities propel people and enable them to do great things and overcome significant hurdles."

Patient Persistence is both motivational and inspirational, offering help and hope to anyone who feels that his or her life is out of control, or that things have gotten so bad that there will never be a way to make it better.

Both of these books are available through the EP Library by calling 1-800-535-1910, or by visiting the Website at www. eplibrary.com

Finally, there is a truly portable assistive reading technology that reads words aloud and can be used ANYWHERE!

Readingpen *II*™

The perfect solution for educational needs!

For persons with reading difficulties, learning disabilities and dyslexia

- **SCAN a word(s) from printed text**
- **SEE the word displayed in large characters**
- **HEAR the word read aloud from built-in speaker or earphone**
- **DEFINE the word and hear it spoken aloud**

- Scans and speaks word or full line of text
- Displays and speaks the dictionary definition
- Spells the word out loud
- Displays syllables
- Recognizes printed fonts (6-22 points), **bold**, *italic*, underlined, hyphenated, and inverted text
- Adjustable for left and right-handed users
- Keeps a history of the last 80 words scanned
- Contains over 200,000 definitions from the American Heritage College Dictionary 3rd Edition
- Ergonomic 6" x 1 1/2" x 1" and lightweight (only 3 oz.)
- An Opticard lets you input text manually

For more information, please call toll free
1-888-777-0552 or 1-877-773-2363
Website: www.wizcomtech.com

Not recommended for persons with low vision or impaired fine motor control.

Circle #139 or visit www.eparent.com/adinfo

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #122 or visit www.eparent.com/adinfo

FAMILY VOICES STATE CONTACT LIST

Family Voices is a national grassroots network of families and friends speaking on behalf of children with special health care needs. The principles of Family Voices are as follows. Every child deserves quality primary and specialty health care that is affordable and within geographic reach. Families are the core of this nation's health system, their children's most important health providers and caregivers. Quality health care is family-centered, community-based, coordinated, and culturally competent.

Family-centered health benefits and services are flexible, and guided by what children need. Strong family-professional partnerships improve decision-making, enhance outcomes, and assure quality. Families practice cost-effectiveness and expect the same from our health systems and services. Members of the Network serve on local, state and national boards and task forces. Often times members are staff for state health agencies or parent organizations, advisors to private and public health systems and research projects. The mission is to bring the family perspective to policy discussions and decisions. Listed below by state and US Territories are the Family Voices Coordinators or Chapter Representatives. For additional information, contact Family Voices National Office at phone: (888) 835-5669 or (505) 872-4774; e-mail: kidshealth @familyvoices.org; Web site: http://www.familyvoices.org.

STATE	NAME	TEL	E-MAIL
ALABAMA	SUSAN COLBURN	(334) 613-2284	SCOLBURN@REHAB.STATE.AL.US
ALASKA	KATHY ALLELY	(907) 269-5231	KATHYALLELY@HEALTH.STATE.AK.US
ARIZONA	JUDIE WALKER	(602) 242-4366X116	WALKJAWS@AOL.COM
ARKANSAS	RODNEY FARLEY	(501) 682-1461	REFARLEY@JUNO.COM
CALIFORNIA	JUNO DUENAS LINDA SWAN	(415) 282-7494 (415) 282-7494	
COLORADO	CHRISTY BLAKELY	(303) 973-5780	
CONNECTICUT	MOLLY COLE	(860) 679-1504	MCOLE@NSO1.UCHC.EDU
DELAWARE	BETH MACDONALD	(302) 697-1976	BMACDONFV@JUNO.COM
DISTRICT OF COLUMBIA	GAIL JOHNSON ANDERSON	(410) 859-5304	FAMILYVOICESOFDC@HOTMAIL.COM
FLORIDA	LINDSAY PHILLIPS	(850) 926-3514	
GEORGIA	CINDY ARCENEAUX	(770) 338-2390	CARCENEAUX@AOL.COM
HAWAII	LEOLINDA PARLIN	(808) 524-8313	LEOLIINDA@RESQCONSULTANTS
IDAHO	ELLEN HUNT-LANDRY	(208) 376-3968	ELLENFCF@EARTHLINK.NET
ILLINOIS	FAYE MANASTER ELDAR	(773) 274-8683 (888) 950-8683	FAMILYVOICESILLINOIS@YAHOO.COM
INDIANA	DONNA GORE OLSEN	(317) 257-8683	FAMVOICESIN@AOL.COM
IOWA	PAULA S. CONNOLLY	(515) 223-6714	LDNAIOWA@HOTMAIL.COM
KANSAS	CONNIE ZIENKEWICZ	(316) 945-7747 (888) 815-6364	FMIN@FEIST.COM
KENTUCKY	VERONICA BROWN	(502) 479-7465 (877) 611-7465 (KY ONLY)	
LOUISIANA	PHYLLIS RATCLIFFE	(504) 568-5055	FAMILYLA@BELLSOUTH.NET
MAINE	BEVERLY BAKER	(207)582-2504	BBAKER@MPF.ORG
MARYLAND	JOSIE THOMAS	(410) 859-5300	JOSIIE@PPMD.ORG
MASSACHUSETTS	POLLY SHERMAN	(508) 947-1231	POLLY.SHERMAN@STATE.MA.US
MICHIGAN	LAURA MARSHALL	(810) 232-2055	RADAMS@VOYAGER.NET
MINNESOTA	CAROLYN ALLSHOUSE	(800) 537-2237	CALLSHOUSE@PACER.ORG
MISSISSIPPI	ARETHA LEE	(800) 366-5707	
MISSOURI	SARAH ZERR MUNDAY	(816) 455-2977	SHZKCMO@AOL.COM
MONTANA	TERA RANDALL	(406) 232-6321	RANDALLRACEN@MCN.NET
NEBRASKA	RENE FERDINAND	(402) 475-4407	
NEVADA	MARCIA O'MALLEY	(775) 784-4921X3003	MOMALLEY@UNR.EDU
NEW HAMPSHIRE	MARTHA JEAN MADISON	(603) 271-4525	MJM10KIDS@HOTMAIL.COM
NEW JERSEY	LAUREN AGORATUS LOUISE MCINTOSH	(609) 584-5779 (908) 277-2883	
NEW MEXICO	PATRICIA HOLMES	(505) 247-0192	NMFAMILYVOICES@AOL.COM
	GAY FINLAYSON	(505) 272-1046	
NEW YORK	RUTH WALDEN	(518) 474-2001	RXW303@HEALTH.STATE.NY.US
NORTH CAROLINA	GRACE SISCO	(704) 892-1321 (800) 962-6817 (NC ONLY)	ECACNCFV@AOL.COM
NORTH DAKOTA	DONENE FEIST	(701) 493-2333	
OHIO	KATHY BACHMANN	(614) 752-2930	

continued on page 126

FINDING A CHILD CARE PROVIDER YOU CAN TRUST JUST GOT EASIER

Experts know that a child's early experience has a lasting impact on his or her ability to learn and succeed in school. Choose Easter Seals - high-quality care you can trust.

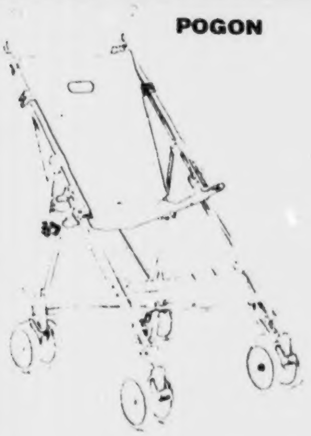
- 80 years *of helping children*
- *Full day,* year round *early care and education*
- Individualized *learning*
- Children *6 months to 5 years*
- NAEYC *standards*
- Safe, *child-friendly environments with* age-appropriate *toys and stimulating* educational *activities*
- Partnering *with parents for* positive *outcomes*

child development centers
a fun place to learn and grow

To learn more, contact

Easter Seals
230 W. Monroe Street
Suite 1800
Chicago, IL 60606-4802
312.726.6200
www.easter-seals.org

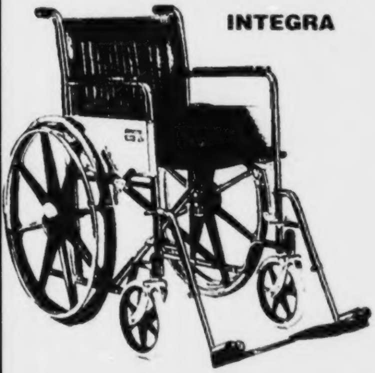
Circle #97 or visit www.eparent.com/adinfo


POGON

ROVER EXPRESS

MICRO SHELL

MANUAL STAND-UP

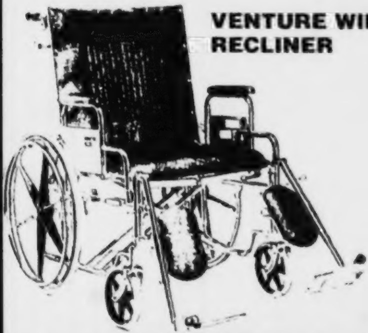

INTEGRA

- THERADYNE offers a complete line of Manual and Power Wheelchairs, including Pediatric, Bariatric and Stand-Up.
- Our Wheelchair Line meets all applicable Medicare coding.
- Our Pediatric Seating Line features the popular POGON STROLLER and MICRO-SHELL Modular Seating System.
- Bariatric Seating: VENTURE PLUS has a weight capacity of 800 lbs.
- Theradyne Fitness: Offers a full line of treadmills for both personal and commercial applications.
- Request Further Informaton on Theradyne Products from your dealer, or call us direct at our Minnesota factory.

theradyne Rehab

theradyne A DIVISION OF KURT

theradyne fitness


VENTURE WIDE RECLINER

Toll Free Customer Service

1-800-328-4014

Web Site

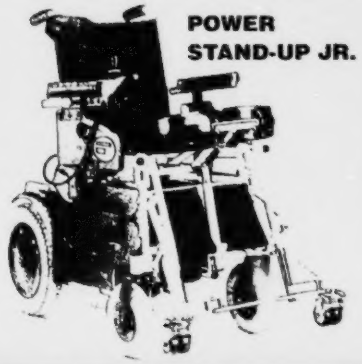
www.theradyne.com

KURT K

KURT MANUFACTURING COMPANY
395 Ervin Industrial Drive
Jordan, MN 55352

129

Circle #129 or visit www.eparent.com/adinfo


POWER STAND-UP JR.

FAMILY VOICES STATE CONTACT LIST

continued from page 123

STATE	NAME	TEL	E-MAIL
OKLAHOMA	LYN LAND	(405) 373-3300 (800) 766-2223 (OK ONLY)	THORESONL@AOL.COM
OREGON	BECKY ADELMANN	(503) 297-3453	ADELMANN@OHSU.EDU
PENNSYLVANIA	SUSAN BADEAU	(215) 844-6641	SBADEAU@AOL.COM
	MARYBETH ZAHORCHAK	(724) 538-4458	QZAHORCHAK@AOL.COM
PUERTO RICO	PEDRO CRUZ	(787) 738-0454	PEDROCRUZ82@HOTMAIL.COM
RHODE ISLAND	DAWN WARDYGA	(401) 727-4144X58 (800) 464-3399X58 (RI ONLY)	FAMILYVOICES@RIPIN.ORG
SOUTH CAROLINA	CRAIG STOXEN	(803) 750-6988	CRAIG@SCAUTISM.ORG
SOUTH DAKOTA	DINA MICKE	(605) 361-3171	DMICKE@ADPARENT.ORG
TENNESSEE	DARA HOWE	(615) 383-9442X13	
TEXAS	BRAD THOMPSON	(888) 352-5647	BTHOMPSON@SOUTHWESTCOFC.ORG
UTAH	GINA POLA-MONEY	(801) 562-2582	UTAHFAMILYVOICES@JUNO.COM
VERMONT	NANCY DIVENERE KAY VAN WOERT	(802) 655-5290 (802) 985-5668	NANCY.DIVENERE@PARTOPARVT.ORG
VIRGIN ISLANDS	CHERYL MILLER	(340) 776-6179	MANGOMOMMA@YAHOO.COM
VIRGINIA	HEATHER BENNETT MCCABE	(703) 960-2361X346	
WASHINGTON	JUDIE EBBERT-RICH	(360) 866-8254	JUDIERICH@OLYWA.NET
WEST VIRGINIA	GAIL A. FOILY	(304) 873-1834	GFOLEY@IOLINE.NET
WISCONSIN	LIZ HECHT	(608) 263-7148	HECHT@WAISMAN.WISC.EDU
WYOMING	DIANE MAGILL	(307) 635-5999	LOBOMAGILL@WYOMING.COM

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

Release Date February '02!

Coming soon!

Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child..

by R. A. Neubauer, M.D.

Dr. Neubauer's new book is a complete guide written for the professional as well as the caregiver of exceptional children. The book describes the latest information on hyperbaric oxygenation therapy including improved brain function as visualized through functional imaging. Clinical and scientific data along with references are included.

Call 1-800-552-0255 to order.

Ocean Hyperbaric Neurologic Center (formerly Ocean Hyperbaric Center) adopts a new name to focus on treating neurologic conditions with the same great reputation, experience and quality care. **Dr. Richard A. Neubauer**, Medical Director, has for over 30 years pioneered for hyperbaric oxygenation treatment and is pleased to continue to operate the only hyperbaric oxygenation center in the world dedicated soley to the treatment of neurological conditions.

If you are seeking a hyperbaric oxygenation therapy provider for your special child, Ocean Hyperbaric Neurologic Center offers top medical expertise, experience, an established reputation for excellence and the best in quality patient care.

(800) 552-0255
• Call for free video & information

For more information visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

Circle #100 or visit www.eparent.com/adinfo

STATE PROTECTION AND ADVOCACY AGENCIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES, MENTAL ILLNESS AND THE CLIENT ASSISTANCE PROGRAM (P&AS)

State Protection and Advocacy (P&As) offices are federally mandated to provide legally based advocacy services to people with disabilities in each state and territory. P&As primarily advocate on behalf of special education students through funds from two federal programs—Protection and Advocacy for People with Developmental Disabilities **(PADD)** and Protection and Advocacy for Individual Rights **(PAIR)**. These two programs join two other programs—Protection and Advocacy for Individuals with Mental Illness **(PAIMI)** and the Client Assistance Program **(CAP)**—to complete the entire P&A System.

P&As all over the country work on a variety of cases with common themes for people with disabilities, one of which is ensuring that children in special education are receiving the services to which they are entitled under IDEA. The P&A System provides a unique and effective resource for disability rights advocacy and education. People with disabilities, their family members, and representatives are encouraged to make use of these services. Consistent with available resources and priorities established by the community, the P&A will make every effort to provide appropriate assistance to remedy the situation.

For additional information about the P&A System, including the location of all P&As nationwide, contact the National Association of Protection and Advocacy Systems (NAPAS), telephone (202) 408-9514 (Voice) or (202) 408-9521 (TDD); or visit their Web site: http://www.protectionandadvocacy.com. For information about an individual case or local resources, see the following directory of state listings.

Using This Directory

When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard http:// before each. E-mail addresses are indicated by the symbol ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

CAP
Jerry Norsworthy
Division of Rehabilitation Services
and Children's Rehabilitation
Services
2125 East South Blvd.
Montgomery, AL 36116
Phone: 800-228-3231
(Voice/TDD in AL only)
800-441-7607 (outside AL)
Fax: 334-288-1104
✉sacap2000@yahoo.com
Website: http://sacap.homestead.com/SACAPPage1.html

PADD/PAIMI/PAIR
Reuben Cook, Executive Director
Alabama Disabilities
Advocacy Program
The University of Alabama
Box 870395
Tuscaloosa, AL 35487-0395
Phone: 205-348-4928
205-348-9484 (TTD)
800-826-1675
Fax: 205-348-3909
✉rcook@law.ua.edu
Website: www.adap.net

ALASKA

CAP
Pam Stratton, CAP Director
ASIST
2900 Boniface Parkway, #100
Anchorage, AK 99504-3195
Phone: 907-333-2211
800-478-0047
Fax: 907-333-1186
✉akcap@alaska.com

PADD/PAIMI/PAIR
Dave Fleurant,
Acting Executive Director
Disability Law Center of Alaska
3330 Arctic Blvd., Suite 103
Anchorage, AK 99503
Phone: 907-565-1002
800-478-1234 (Voice/TDD)
Fax: 907-565-1000
✉dfleurant@dlcak.org
Website: www.dlcak.org

AMERICAN SAMOA

CAP/PADD/PAIMI/PAIR
Marie Ma'o, Executive Director
Client Assistance Program and
Protection & Advocacy
P. O. Box 3937
Pago Pago,
American Samoa 96799
Phone: 011-684-633-2441
Fax: 011-684-633-7286
✉marie@samoatelco.com

ARIZONA

CAP/PADD/PAIMI/PAIR
Leslie Cohen, Executive Director
Arizona Center for Disability Law
100 North Stone Avenue,
Suite 305
Tucson, AZ 85701
Phone: 520-327-9547
800-922-1447 (Voice/TTY)
Fax: 520-884-0992
✉lcohen@acdl.com
Website: www.acdl.com

ARKANSAS

CAP/PADD/PAIMI/PAIR
Nan Ellen East, Executive Director
Disability Rights Center, Inc.
Evergreen Place, Suite 201
1100 North University
Little Rock, AR 72207
Phone: 501-296-1775
800-482-1174 (Voice/TDD)
Fax: 501-296-1779
✉panda@arkdisabilityrights.org/
✉naneast@hotmail.com
Website:
www.advocacyservices.org

CALIFORNIA

CAP
Sheila Conlon-Mentkowski,
Chief Client Assistance Program
Department of Rehabilitation
2000 Evergreen Street
Sacramento, CA 95815
Phone: 916-263-7372
800-952-5544 (Voice)
916-263-7465
800-598-3273 (TTY)
Fax: 916-263-7464
✉smentkow@dor.ca.gov
Website: www.rehab.cahwnet.gov

PADD/PAIMI/PAIR
Catherine Blakemore,
Executive Director
Protection & Advocacy, Inc.
100 Howe Avenue, Suite 185N
Sacramento, CA 95825
Phone: 916-488-9955
Admin. Off. 916-488-9950
Legal Off. 800-776-5746
Fax: 916-488-2635 or 9962
✉catherine.blakemore@pai-ca.org
✉legalmail@pai-ca.org
Website: www.pai-ca.org

COLORADO

CAP/PADD/PAIMI/PAIR
Mary Anne Harvey,
Executive Director
The Legal Center
455 Sherman Street, Suite 130
Denver, CO 80203
303-722-0300 (Voice/TDD)
800-288-1376
Fax: 303-722-0720
✉maharvey@thelegalcenter.org
✉tlcmail@thelegalcenter.org
Website: www.thelegalcenter.org

CONNECTICUT

CAP/PADD/PAIMI/PAIR
Jim McGaughey,
Executive Director
Office of P&A for Persons
with Disabilities
608 Weston Street
Hartford, CT 06120-1551
Phone: 860-297-4300
860-566-2102 (TDD)
800-842-7303 (statewide)
Fax: 860-566-8714
✉james.mcgaughey@po.state.ct.us/
Website: www.state.ct.us/opapd/

DELAWARE

CAP
Melissa H. Shahan, CAP Director
Client Assistance Program
United Cerebral Palsy, Inc.
254 East Camden-
Wyoming Avenue
Camden, DE 19934
Phone: 302-698-9336
800-640-9336
Fax: 302-698-9338
✉capucp@magpage.com

PADD/PAIMI/PAIR
James McGiffin, Executive
Director / Brian Hartman,
Administrator
Community Legal Aid Society, Inc.
Community Services Building,
Suite 801
100 W. 10th Street
Wilmington, DE 19801
302-575-0660 (Voice/TDD)
Fax: 302-575-0840
✉bjh@diamondnet.org

DISTRICT OF COLUMBIA

CAP/PADD/PAIMI/PAIR
Jane Brown, Executive Director
University Legal Services
300 I Street, NE, Suite 202
Washington, DC 20002
Phone: 202-547-0198
Fax: 202-547-2083
✉jbrown@uls-dc.com

FLORIDA

CAP/PADD/PAIMI/PAIR
Gary Blumenthal,
Executive Director
Advocacy Ctr. for Persons
w/Disabilities
2671 Executive Center, Circle W.
Webster Building, Suite 100
Tallahassee, FL 32301-5024
Phone: 850-488-9071
800-342-0823
800-346-4127 (TDD)
Fax: 850-488-8640
✉g.blumenthal@advocacycenter.org
Website: www.advocacycenter.org

GEORGIA

CAP
Charles L. Martin, CAP Director
Georgia Client Assistance Program
123 N. McDonough
Decatur, GA 30030
Phone: 404-373-3116
Fax: 404-373-4110
✉GaCAPDirector@theOmbudsman.com
Website:
www.theOmbudsman.com

Department of Human Resources
Division of Rehab. Service
2 Peachtree St., NW,
Room 23-307
Atlanta, GA 30303
Phone: 404-657-3003
Fax: 404-657-7855

PADD/PAIMI/PAIR
Joyce Ringer
Georgia Advocacy Office, Inc.
100 Crescent Centre Parkway,
Suite 520
Tucker, GA 30084
Phone: 404-885-1234
800-537-2329 (Voice/TDD)
Fax: 770-414-2948
✉ringer@thegao.org
✉info@thegao.org
Website: ul451.gsu.edu/gao/

GUAM

CAP
Edmund Cruz, Executive Director
Parent-Agencies Network, CAP
J. Madarang Dental Bldg.
2238 Route 16, Suite 1-B
PO Box 23474
GMF, Guam 96921
Phone: 1-671-637-4227
Fax: 1-671-637-4211
✉capguam@ite.net

PADD/PAIMI/PAIR
Daniel Somerfleck,
Executive Director
Guam Legal Services
113 Bradley Place
Hagatna, Guam 69610
Phone: 1-671-477-9811
Fax: 1-671-477-1320
✉glsc@netpci.com

HAWAII

CAP/PADD/PAIMI/PAIR
Gary Smith, Executive Director
Hawaii Disability Rights Center
900 Front Street Mall, Suite 1040
Pioneer Plaza
Honolulu, HI 96813
808-949-2922 (Voice/TDD)
Fax: 808-949-2928
✉gls@pixi.com
✉pahi@pixi.com
Website: www.pixi.com/~pahi

IDAHO

CAP/PADD/PAIMI/PAIR
Jim Baugh, Executive Director
Co-Ad, Inc.
4477 Emerald, Suite B-100
Boise, ID 83706
208-336-5353 (Voice/TDD)
800-632-5125
Fax: 208-336-5396
✉coadinc@qwest.net
✉jrbaugh@qwest.net
Website: users.moscow.com/co-ad

ILLINOIS

CAP
Cynthia Grothuas, CAP Director
Illinois Client Assistance Program
100 N. First Street, 1st Floor
Springfield, IL 62702
Phone: 217-782-5374
Fax: 217-524-1790
✉dhsvred@dhs.state.il.us

PADD/PAIMI/PAIR
Zena Naiditch, Executive Director
Equip for Equality, Inc.
11 East Adams, Suite 1200
Chicago, IL 60603
312-341-0022 (Voice/TDD)
800-537-2632
Fax: 312-341-0295
✉zena@equipforequality.org
Website:
www.equipforequality.org

INDIANA

CAP/PADD/PAIMI/PAIR
Tom Gallagher,
Executive Director Indiana
Protection and Advocacy Services
4701 N. Keystone Ave., Suite 222
Indianapolis, IN 46204
317-722-5555 (Voice/TDD)
800-622-4845
Fax: 317-722-5564
✉tgallagher@ipas.state.in.us

IOWA

CAP
Harlietta Helland, CAP Director
Client Assistance Program
Division on Persons w/Disabilities
Lucas State Office Building
Des Moines, IA 50310
Phone: 515-281-3957
800-652-4298
Fax: 515-242-6119
✉harlietta.helland@dhr.state.ia.us

STATE PROTECTION AND ADVOCACY AGENCIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES, MENTAL ILLNESS AND THE CLIENT ASSISTANCE PROGRAM (P&AS)

PADD/PAIMI/PAIR
Sylvia Piper, Executive Director
Iowa P&A Service, Inc.
3015 Merle Hay Road, Suite 6
Des Moines, IA 50310
Phone: 515-278-2502
515-278-0571 (TDD)
800-779-2502
Fax: 515-278-0539
✉spiper@ipna.org/info@ipna.org

KANSAS

CAP
Mary Reyer, CAP Director
Client Assistance Program
3640 SW Topeka Blvd., Suite 150
Topeka, KS 66611
Phone: 785-266-8193
800-432-2326
Fax: 785-266-8574
✉msr@srskansas.org
✉dxlm@srskansas.org
Website:
www.ink.org/public/srs/CAP

PADD/PAIMI/PAIR
Jim Germer, Executive Director
Kansas Advocacy
& Protection Services
3745 SW Wanamaker Road
Topeka, KS 66610
Phone: 785-273-9661
Fax: 785-273-9414
✉jim@ksadv.org

KENTUCKY

CAP
Gerry Gordon-Brown,
CAP Director
Client Assistance Program
209 St. Clair, 5th Floor
Frankfort, KY 40601
Phone: 502-564-8035
800-633-6283
Fax: 502-564-2951
✉Gerry.Gordon-Brown@mail.state.ky.us

PADD/PAIMI/PAIR
Maureen Fitzgerald,
Executive Director
Office for Public Advocacy
Division for P&A
100 Fair Oaks Lane, 3rd Floor
Frankfort, KY 40601
Phone: 502-564-2967
800-372-2988 (TDD)
Fax: 502-564-0848
✉mfitzgerald@mail.pa.state.ky.us

LOUISIANA

CAP/PADD/PAIMI/PAIR
Lois Simpson, Executive Director
Advocacy Center
225 Baronne, Suite 2112
New Orleans, LA 70112-2112
504-522-2337 (Voice/TDD)
800-960-7705
Fax: 504-522-5507
✉Simplo@advocacyLA.org

MAINE

CAP
Steve Beam
CARES, Inc.
4-C Winter Street
Augusta, ME 04330
Phone: 207-622-7055
800-773-7055
Fax: 207-621-1869
✉capsite@aol.com

PADD/PAIMI/PAIR
Kim Moody, Executive Director
Disability Rights Center
24 Stone Street
P.O. Box 2007
Augusta, ME 04338
Phone: 207-626-2774
800-452-1948 TDD
Fax: 207-621-1419
✉advocate@drcme.org
Kim: ✉kmoody@drcme.org

MARYLAND

CAP
Beth Lash, CAP Director
Client Assistance Program
Maryland Rehabilitation Center
Division of Rehabilitation Services
2301 Argonne Drive
Baltimore, MD 21208
Phone: 410-554-9358
800-638-6243
Fax: 410-554-9362
✉CAP.DORS.MD@visto.com

PADD/PAIMI/PAIR
Philip Fornaci, Executive Director
Maryland Disability Law Center
Central Maryland Office
The Walbert Building, Suite 400
1800 North Charles Street
Baltimore, MD 21201
Phone: 410-727-6352
800-233-7221
410-727-6387 (TDD)
Fax: 410-727-6389
Fax:410-234-2711
✉philf@mdlcbalto.org

MASSACHUSETTS

CAP
Barbara Lybarger, CAP Director
MA Office on Disability
Client Assistance Program
One Ashburton Place, Room 1305
Boston, MA 02108
Phone: 617-727-7440
Fax: 617-727-0965
✉Barbara.Lybarger@modi.state.ma.us
Website: www.state.ma.us/mod/MSCAPBRO.html

PADD/PAIR
Christine Griffin,
Executive Director
Disability Law Center, Inc.
11 Beacon Street, Suite 925
Boston, MA 02108
617-723-8455 (Voice/TDD)
Fax: 617-723-9125
✉cgriffin@dlc-ma.org
Website: www.dlc-ma.org/

PAIMI
Bob Fleischner
Center for Public Representation
22 Green Street
Northampton, MA 01060
413-586-6024 (Voice/TDD)
Fax: 413-586-5711
✉rfleischner@gbls.org

MICHIGAN

CAP/PADD/PAIMI/PAIR
Michele Wallace,
Acting Executive Director
Michigan P&A Services
106 West Allegan, Suite 300
Lansing, MI 48933
517-487-1755 (Voice/TDD)
CAP only: 1-800-292-5896
Fax: 517-487-0827
✉mwallac@mpas.org
Website: www.mpas.org

MINNESOTA

CAP/PADD/PAIMI/PAIR
Lisa Cohen, Administrator
Minnesota Disability Law Center
430 First Avenue North, Suite 300
Minneapolis, MN 55401-1780
Phone: 612-332-1441
800-292-4150
Fax: 612-334-5755
✉lcohen@midmnlegal.org

MISSISSIPPI

CAP
Presley Posey, CAP Director
Client Assistance Program
Easter Seal Society
3226 N. State Street
Jackson, MS 39216
Phone: 601-982-7051
Fax: 601-982-1951
✉pposey8803@aol.com

PADD/PAIMI/PAIR
Rebecca Floyd, Executive Director
Mississippi P&A
System for DD, Inc.
5305 Executive Place, Suite A
Jackson, MS 39206
601-981-8207 (Voice/TDD)
Fax: 601-981-8313
✉mspna@bellsouth.net

MISSOURI

CAP/PADD/PAIMI/PAIR
Shawn de Loyola,
Executive Director
Missouri P&A Services
925 S. Country Club Drive,
Unit B-1
Jefferson City, MO 65109
Phone: 573-893-3333
800-392-8667
Fax: 573-893-4231
✉mopasjc@socket.net
Website:
www.members.socket.net/-mopasjc/MOP&A.htm

MONTANA

CAP/PADD/PAIMI/PAIR
Bernadette Franks-Ongoy,
Executive Director
Montana Advocacy Program
400 North Park, 2nd Floor
PO Box 1681
Helena, MT 59624
406-449-2344 (Voice/TDD)
800-245-4743
Fax: 406-449-2418
✉bernie@mtadv.org
Website: www.mtadv.org

NATIVE AMERICAN

PADD
Therese Yanan, Executive Director
DNA-People's Legal Services, Inc.
P.O. Box 392
Shiprock, NM 87240
Phone: 505-368-3216
Fax: 505-368-3220
✉napap@cyberport.com
✉tyanan@cyberport.com

NEBRASKA

CAP
Victoria Rasmussen, CAP Director
Division of Rehabilitation Services
Nebraska Department of Ed.
301 Centennial Mall South
Lincoln, NE 68509
Phone: 402-471-3656
800-742-7594
Fax: 402-471-0117
✉Vicki_r@nde4.nde.state.ne.us

PADD/PAIMI/PAIR
Timothy Shaw, Executive Director
Nebraska Advocacy Services, Inc.
522 Lincoln Center Building
215 Centennial Mall South
Lincoln, NE 68508
402-474-3183 (Voice/TDD)
Fax: 402-474-3274
✉Tim@nas-pa.org

NEVADA

CAP
William Bauer, CAP Director
Client Assistance Program
2450 Wrondel Way, Ste E
Reno, NV 89502
Phone: 775-688-1440
800-633-9879
Fax: 775-688-1627
✉wbauer@nvdetr.org
Website:
members.delphi.com/nvcap/index.html

PADD/PAIMI/PAIR
Jack Mayes, Executive Director
Nevada Advocacy
& Law Center, Inc.
6039 Eldora Avenue, Ste C- 3
Las Vegas, NV 89146
Phone: 702-257-8150
702-257-8160 (TDD)
888-349-3843
Fax: 702-257-8170
✉ndalc@earthlink.net (Las Vegas)
✉JMayes9524@aol.com
✉reno@ndalc.org (Reno office)
Website: www.ndalc.org

NEW HAMPSHIRE

CAP
Bill Hagy, Ombudsman
Client Assistance Program
Governor's Commission
on Disability
57 Regional Drive
Concord, NH 03301-9686
Phone: 603-271-2773
Fax: 603-271-2837
✉bhagy@gov.state.nh.us
Website:
www.state.nh.us/disability/caphomepage.html

PADD/PAIMI/PAIR
Donna Woodfin,
Executive Director
Disabilities Rights Center
P.O. Box 3660
18 Low Avenue
Concord, NH 03302-3660
603-228-0432 (Voice/TDD)
Fax: 603-225-2077
✉DonnaW@drcnh.org

NEW JERSEY

CAP/PADD/PAIMI/PAIR
Sarah Wiggins-Mitchell,
Executive Director
New Jersey P&A, Inc.
210 S. Broad Street, 3rd Floor
Trenton, NJ 08608
Phone: 609-292-9742
800-922-7233
Fax: 609-777-0187
✉advoca@njpanda.org
✉smitch@njpanda.org
Website: www.njpanda.org

NEW MEXICO

CAP/PADD/PAIMI/PAIR
James Jackson, Executive Director
Protection & Advocacy, Inc.
1720 Louisiana Blvd., NE,
Suite 204
Albuquerque, NM 87110
Phone: 505-256-3100
800-432-4682 (Voice/TDD)
Fax: 505-256-3184
✉nmpajackson@hotmail.com
Website:
www.nmprotection-advocacy.com

NEW YORK

CAP/PADD/PAIMI/PAIR
Gary O'Brien, Executive Director
NYS Commission on
Quality of Care
for the Mentally Disabled
401 State Street
Schenectady, NY 12305-2397
Phone: 518-381-7098
800-624-4143 (TDD)
Fax: 518-381-7095
✉cqc.state.ny.us
✉garyo@cqc.state.ny.us
Website: www.cqc.state.ny.us

NORTH CAROLINA

CAP
Kathy Brack, CAP Director
North Carolina Department of
Health & Human Services
Client Assistance Program
2801 Mail Service Center
Raleigh, NC 27611
Phone: 919-733-6300
800-215-7227
Fax: 919-715-2456
✉Kathy.Brack@ncmail.net

PADD/PAIMI/PAIR
Allen Perry, Executive Director
Governor's Advocacy Council
for Persons with Disabilities
2113 Cameron Street, Suite 218
Raleigh, NC 27605
919-733-9250 (Voice/TDD)
800-821-6922
Fax: 919-733-9173
✉allen.perry@ncmail.net
Website:
www.doa.state.nc.us/doa/gacpd/gacpd.htm

NORTH DAKOTA

CAP
Dennis Lyon, CAP Director
Client Assistance Program
600 South 2nd Street, Suite 1B
Bismarck, ND 58504-4038
Phone: 701-328-8947
800-207-6122 (CAP only)
Fax: 701-328-8969
✉solyod@state.nd.us

PADD/PAIMI/PAIR
Teresa Larsen, Executive Director
North Dakota Protection &
Advocacy Project
400 E. Broadway, Suite 616
Bismarck, ND 58501
Phone: 701-328-2950
800-472-2670
800-642-6694 (24 hr. Hotline)
800-366-6888 (TDD)
Fax: 701-328-3934
✉tlarsen@state.nd.us
Website: www.ndpanda.org

N. MARIANAS ISLANDS

CAP/PADD/PAIMI/PAIR
Lydia Santos, Executive Director
Northern Marianas Protection and
Advocacy System, Inc.
P.O. Box 503529
Saipan, MP 96950-3529
Phone: 1-670-235-7274/3
Fax: 1-670-235-7275
✉nmpasi@gtepacifica.net

OHIO

CAP/PADD/PAIMI/PAIR
Carolyn Knight, Executive Director
Ohio Legal Rights Service
8 East Long Street, 5th Floor
Columbus, OH 43215
614-466-7264 (Voice/TDD)
800-282-9181
Fax: 614-644-1888
✉CKnight@olrs.state.oh.us
Website: www.state.oh.us/olrs/

OKLAHOMA

CAP
James Sirmans, CAP Director
Client Assistance Program
Oklahoma Office of
Handicapped Concerns
2712 Villa Prom
Oklahoma City, OK 73107
Phone: 405-521-3756
800-522-8224
Fax: 405-522-6695
✉James.Sirmans@ohc.state.ok.us
Website:
www.state.ok.us/~ohc/cap.htm

PADD/PAIMI/PAIR
Kayla Bower, Executive Director
Oklahoma Disability
Law Center, Inc.
2915 Classen Blvd., Suite 300
Oklahoma City, OK 73106
Phone: 405-525-7755
800-880-7755
Fax: 405-525-7759
✉odlcokc@flash.net
✉kbower1@flash.net
Website:
www.oklahomadisabilitylaw.org

OREGON

CAP
Client Assistance Program
Oregon Advocacy Center
620 Southwest Fifth Avenue,
5th Floor
Portland, OR 97204-1428
Phone: 503-243-2081
800-452-1694
800-556-5351 (TDD)
Fax: 503-243-1738
✉welcome@oradvocacy.org

PADD/PAIMI/PAIR
Robert Joondeph,
Executive Director
Oregon Advocacy Center
620 SW Fifth Ave., 5th Floor
Portland, OR 97204-1428
Phone: 503-243-2081
800-452-1694
800-556-5351 (TDD)
Fax: 503-243-1738
✉bob@oradvocacy.org or
✉welcome@oradvocacy.org
Website: www.oradvocacy.org

PENNSYLVANIA

CAP
Stephen Pennington, CAP
Director
Center for Disability Law & Policy
1617 JFK Blvd., Suite 800
Philadelphia, PA 19103
Phone: 215-557-7112
888-745-2357
Fax: 215-557-7602
✉info@equalemployment.org

PADD/PAIMI/PAIR
Kevin Casey, Executive Director
Pennsylvania P&A, Inc.
1414 N. Cameron Street, Suite C
Harrisburg, PA 17103
717-236-8110 (Voice/TDD)
800-692-7443
Fax: 717-236-0192
✉ppa@ppainc.org

PUERTO RICO

CAP/PADD/PAIMI/PAIR
Jose Raul Ocasio,
Executive Director
Office of the Governor
Ombudsman for the Disabled
P. O. Box 41309
San Juan, PR 00940-1309
Phone: 787-721-4299
787-725-2333
800-981-4125
TTY: 787-4014
Fax: 787-721-2455
✉jrocasio@oppi.prstar.net
✉mromero@oppi.prstar.net
Website: www.oppi.prstar.net

RHODE ISLAND

CAP/PADD/PAIMI/PAIR
Ray Bandusky, Executive Director
Rhode Island Disability
Law Center Inc.
349 Eddy Street
Providence, RI 02903
Phone: 401-831-3150
401-831-5335 (TDD)
800-733-5332
Fax: 401-274-5568
✉rbandusky@ridlc.org/
✉hn7384@handsnet.org

SOUTH CAROLINA

CAP
Dr. Larry Barker, CAP Director
Office of the Governor
Division of Ombudsman
& Citizen Services
1205 Pendleton Street
P. O. Box 11369
Columbia, SC 29211
Phone: 803-734-0457
800-868-0040
Fax: 803-734-0546
✉mbutler@govoepp.state.sc.us /
✉lbarker@govoepp.state.sc.us
Website:
www.govoepp.state.sc.us/cap

PADD/PAIMI/PAIR
Gloria Prevost, Executive Director
Protection & Advocacy for People
with Disabilities, Inc.
3710 Landmark Drive, Suite 208
Columbia, SC 29204
Phone: 803-782-0639
866-275-7273 (Voice/TDD)
Fax: 803-790-1946
✉prevost@
protectionandadvocacy-sc.org

SOUTH DAKOTA

CAP/PADD/PAIMI/PAIR
Robert Kean, Executive Director
South Dakota Advocacy Services
221 South Central Avenue
Pierre, SD 57501
605-224-8294 (Voice/TDD)
800-658-4782
Fax: 605-224-5125
✉keanr@sdadvocacy.com
Website: www.sdadvocacy.com

TENNESSEE

CAP/PADD/PAIMI/PAIR
Shirley Shea, Executive Director
Tennessee P&A, Inc.
P. O. Box 121257
Nashville, TN 37212
Phone: 615-298-1080
800-342-1660 (Voice/TDD)
Fax: 615-298-2046
✉shirleys@tpainc.org

TEXAS

CAP/PADD/PAIMI/PAIR
Mary S. Faithfull, Executive Director
Advocacy, Inc.
7800 Shoal Creek Blvd., Suite 171-E
Austin, TX 78757
512-454-4816 (Voice/TDD)
800-252-9108
Fax: 512-323-0902
✉mfaithful@advocacyinc.org
Website: www.advocacyinc.org

UTAH

CAP/PADD/PAIMI/PAIR
Fraser Nelson, Executive Director
Disability Law Center
455 East 400 South, Suite 410
Salt Lake City, UT 84111
801-363-1347 (Voice/TDD)
800-662-9080
Fax: 801-363-1437
✉fnelson@disabilitylawcenter.org
Website: www.disabilitylawcenter.org

VERMONT

CAP
Nancy Breiden, CAP Director
Vermont Disability Law Project
57 North Main Street, Suite 2
Rutland, VT 05401
Phone: 802-775-0021
800-769-7459
Fax: 802-775-0022
✉nbreiden@vtlegalaid.org

PADD/PAIMI/PAIR
Torin Togut, Executive Director
Vermont Protection & Advocacy
141 Main Street, Suite 7
Montpelier, VT 05602
Phone: 802-229-1355
800-834-7890
Fax: 802-229-1359
✉Ttogut@vtpa.org
Website: www.vtpa.org

VIRGIN ISLANDS

CAP/PADD/PAIMI/PAIR
Amelia Headley-Lamont,
Executive Director
Virgin Islands Advocacy, Inc.
63 Carlton
Frederiksted, VI 00840
Phone: 340-772-1200
340-772-4641 (TDD)
Fax: 340-772-0609
✉viadvocacy@worldnet.att.net
Website: www.viadvocacy.org

VIRGINIA

CAP/PADD/PAIMI/PAIR
Susan Ferguson,
Executive Director
Department for Rights of
Virginians with Disabilities
Ninth Street Office Bldg.
202 North 9th Street, 9th floor
Richmond, VA 23219
804-225-2042 (Voice/TDD)
800-552-3962
Fax: 804-225-3221
✉fergusst@drvd.state.va.us
Website: www.cns.state.va.
us/drvd

WASHINGTON

CAP
Jerry Johnson, CAP Director
Client Assistance Program
P. O. Box 22510
Seattle, WA 98122
Phone: 206-721-5999
800-544-2121
Fax: 206-721-4537
✉capseattle@att.net

PADD/PAIMI/PAIR
Mark Stroh, Executive Director
Washington P&A System
180 West Dayton, Suite 102
Edmonds, WA 98020
Phone: 425-776-1199
800-562-2702
800-905-0209 (TDD)
Fax: 425-776-0601
Fax: 425-776-0533
✉wpas@wpas-rights.org
✉Mstroh@wpas-rights.org
Website: www.wpas-rights.org

WEST VIRGINIA

CAP/PADD/PAIMI/PAIR
Debbie Mitchem,
Acting Executive Director
West Virginia Advocates, Inc.
Litton Bldg, 4th Floor
1207 Quarrier Street
Charleston, WV 25301
304-346-0847 (Voice/TDD)
800-950-5250
Fax: 304-346-0867
✉dmithcem@wvadvocates.org
Website:
www.newwave.net/~wvadvocates

WISCONSIN

CAP
Linda Vegoe, CAP Director
Department of Agriculture
Trade & Consumer Protection
2811 Agriculture Drive
P.O. Box 8911
Madison, WI 53708-8911
Phone: 608-224-5070
800-362-1290
Fax: 608-224-5069
✉linda.vegoe@datcp.state.wi.us

PADD/PAIMI/PAIR
Lynn Breedlove, Executive
Director
Wisconsin Coalition for Advocacy
16 N. Carroll Street, Suite 400
Madison, WI 53703
Phone: 608-267-0214
608-267-0214 (TTD)
Fax: 608-267-0368
✉lynnb@w-c-a.org (Madison)
✉wcamsn@w-c-a.org
✉wcamke@w-c-a.org (Milwaukee)

WYOMING

CAP/PADD/PAIMI/PAIR
Jeanne Thobro, Executive Director
Wyoming P&A System
320 West 25th Street, 2nd Floor
Cheyenne, WY 82001
Phone: 307-638-7668
307-632-3496
800-821-3091 (Voice/TDD)
800-624-7648
Fax: 307-638-0815
✉wypanda@vcn.com
Website:
www.vcn.com/~wypanda

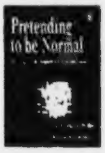
ANGELMAN SYNDROME

Angel Lady
Ashleigh Evans; Alice Evans
Whitney a beautiful, lively, affectionate child disabled by Angelman Syndrome is christened "Angel Lady" by her family. Unable to speak, the family through "Angel Lady Talk" devised a way to communicate. Light-hearted, optimistic and truly inspirational book.
AS100AS **$12.95**

Angelman Syndrome From A to Z
Second Edition
Alice Evans and Julie Hyman
A compilation of tips, hints, and ideas on how to survive and enjoy daily life with a child with Angelman Syndrome. The collection of ideas come from parents, teachers, siblings and care givers of people with Angelman Syndrome from around the world.
AS400AS **$18.95**

ASPERGER SYNDROME

Social Facilitation in Action
A Behavioral Intervention Therapy for Individuals with Autism, Asperger's Syndrome, and Other Related Syndromes
Ilana Katz and Andrew Yellen, PhD
This book provides concrete examples that many children with autism and Asperger's syndrome will encounter in their lives. It uses these examples to show exactly how social facilitation helps these youngsters operate in social situations and understand how society functions.
RL8151AS **$39.95**

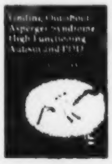


Pretending to be Normal
Living with Asperger's Syndrome
Liane Holliday Willey
This book peers under the umbrella of autism and looks at AS, a relatively new less debilitating autism-related diagnosis. Although first discovered in 1944, not much information has become available until the early 1990s with the establishment of a diagnostic criteria set forth by Gillberg and Gillberg. Here is shown that AS individuals are a bright thread in the tapestry of life and our civilization would be extremely dull and sterile if we did not have and treasure individuals with the condition.
TF250AS **$17.95**

Just This Side of Normal
Glimpses into Life with Autism
Elizabeth King Gerlach
This mothers story captures the challenges of raising a child with autism. She can touch her son, Nicky, but not connect with him; hear but not understand his chanted phrases. Yet she embraces life—the joy and sorrow, hope and despair, frustrations and fear without flinching. This story testifies to the power of a heart that has broken wide open.
FL101AT **$19.95**

Eating an Artichoke
A Mother's Perspective on Asperger's Syndrome
Echo R. Fling
A five year history of a mother, her family and Tim, her son, giving specific accounting of her thoughts and feeling as she struggled to find answers and cope as she raised her children. This book is not an end-all on the subject of raising children with AS but is meant to provide knowledge and understanding of a condition for which little information is available.
TF251AS **$17.95**

Asperger's Syndrome
A Guide for Parents and Professionals
Tony Atwood
This book provides a description and analysis of the unusual characteristics, and practical strategies to reduce those that are most conspicuous or debilitating. There are numerous quotations form people with Asperger's Syndrome, as their insight and descriptions are more clearer and more poignant that the text in scientific journals. This is in layman terms with very little scientific terminology to impress or confuse the reader. Topics covered are: Diagnosis; Social Behavior; Language; Motor Clumsiness, Sensory Sensitivity and much more.
TF252AS **$18.95**



Finding Out About Asperger Syndrome, High Functioning Autism, and PDD
Gunilla Gerland
A must read for all young people who receive a diagnosis of Asperger Syndrome, PDD, or High Functioning Autism. Written by an adult who was diagnosed at a young age with Asperger Syndrome, the book relates to young people, their peers, and their parents so all can better understand the person with the Syndrome.
TF8401AS **$9.95**

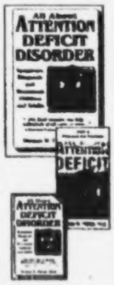
ASTHMA

The Lion Who Had Asthma
Jonathan London
Pictures By Nadine Bernard Westcott
Sean roars like a lion. But the lion who is Sean has asthma, and suddenly it's hard for him to breathe. The whole family pitches in to help deliver the treatment, and soon Sean is King of the Jungle again.
AW5597AM **$14.95**

I'm Tougher than Asthma
Alden R. Carter
and Siri M. Carter
with photographs by Dan Young
A terrific introduction for youngsters to the causes and controls used for Asthma and the discomfort that accompanies it.
AW4749AS **$14.95**

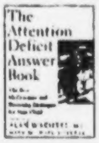
All About Asthma
William and Vivian Ostrow
An effective and friendly tale of one boy's problems with asthma and how he combats them when they occur. With fun illustrations to help the information be more understandable.
AW2766AS **$13.95**

ATTENTION DEFICIT DISORDER



All About Attention Deficit Disorder
Symptoms, Diagnosis and Treatment: Children and Adults
Thomas W. Phelan, Ph.D.
This comprehensive guide, available in book, video set, or audio tape format, gives parents and professionals the information and resources they need to effectively deal with ADD. Includes the most recent developments in ADD research regarding: basic symptoms; effects on school, work, home social life; seven indicators to predict the future; how to treat through counseling, school intervention, behavior management and much more

CM135AD (Book)	**$12.95**
CM140AD (Part I Video)	**$29.95**
CM142AD (Part II Video)	**$29.95**
CM144AD (Both Videos)	**$49.95**
CM145AD (Audio)	**$24.95**



The Attention Deficit Answer Book
The Best Medications and Parenting Strategies for Your Child
Alan Wachtel, MD
with Michael Boyette
This text, written in question and answer format, suggests behavioral techniques, psychological interventions, and school modifications that treat the medical condition as well as the personal, emotional, and social issues arising due to ADHD.
CP176AD **$10.95**

No Apologies for Ritalin
Vidya Bhushan Gupta, MD
This book takes an in-depth look into attention deficit disorder (ADD) and the controversies surrounding treatment. Its purpose is to educate parents of children with ADD about various therapies available, so that they can make informed decisions about the better treatment for their child or young adult. Dr. Gupta hopes that parents of children with ADD will not blame themselves for their child's predicament and will be able to use all available therapies and treatment options, including Ritalin, without guilt.
EP8012AD **$19.95**

No One to Play With
Social Problems of LD and ADD Children
Betty B. Osman, Ph.D.
One of the first books that recognizes and provides advice on how to cope with the social difficulties encountered on an everyday basis by those with learning disabilities and attention deficit disorders.
AT100LD **$15.00**

TAKING CHARGE OF ADHD

The Complete, Authoritative Guide for Parents

RUSSELL A. BARKLEY PH.D.

This revised edition has been updated to incorporate the most current information on ADHD and its treatment. Includes a step by step plan for behavior management; New strategies that give children greater chances of success at school and in social situations; Practical advice for parents on managing stress and keeping peace in the family plus much more.

GL5606AD **$18.95**

WILLIE

Raising and Loving a Child with Attention Deficit Disorder

ANN COLIN

A candid, compelling story of one child, one family, living day to day with ADD, even as they learn to recognize and understand it. Written from a mother's perspective, this uplifting story will surely give hope to many parents who are trying to help their children.

GP177AD **$12.95**

UNLOCKING POTENTIAL

College and Other Choices for People with LD and AD/HD

JULIANA M. TAYMANS, PHD, LYNDA L. WEST, PHD, AND MADELINE SULLIVAN, M.A.

This book is an indispensable tool for high school students with learning disabilities who are preparing for life after graduation. Filled with the latest information, advice, as well as practical tips and resources, this book is designed to make the transition from high school a success.

WB9948AD **$18.95**

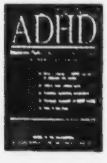
A NEW LOOK AT ADHD

Inhibition, Time, and Self-Control

RUSSELL A. BARKLEY

This video and companion manual provide an easy to understand introduction into one of the most influential theories on the nature and origins of ADHD. Also includes a leader's guide that provides tips on the optimal use of the video with a variety of audiences.

GL4979AD **$99.00**



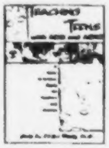
ADHD

Attention Deficit Hyperactivity Disorder in Children and Adults

PAUL H. WENDER, M.D.

This easy to read book for parents, families, and professionals is based on over three decades of research and personal experience in treating affected children and adults with ADD. It is a thorough review of the characteristic features, causes, co-occurring conditions, developmental course, and presentation in adulthood.

OU3489AD **$25.00**



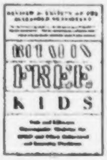
TEACHING TEENS WITH ADD AND ADHD

A Quick Reference Guide for Teachers and Parents

CHRIS A. ZEIGLER DENDY, M.S.

Recognizing the pivotal role teachers play in the long-term success of their students, this book provides information via 75 concise summaries on key issues related to attention deficit disorder. Beyond the thorough review of the basics, this guide also illustrates how the characteristics of the disorder can affect academic performance while presenting strategies interventions and tips to make teacher's jobs easier.

WB7208AD **$18.95**



RITALIN FREE KIDS

Safe and Effective Homeopathic Medicine for ADHD and Other Behavioral and Learning Problems

JUDYTH REICHENBERG-ULLMAN, N.D., M.S.W., AND ROBERT ULLMAN, N.D.

This book describes another approach—one that respects and takes advantage of the diversity of people with symptoms of ADHD; an approach that stimulates the unique adaptive mechanisms each person carries within. Homeopathy is a system of medicine that is highly individualized and can help people move toward optimal health. The case examples in this book demonstrate that, when used alone or as a complement to conventional therapies, homeopathic medicines can improve the function of people with ADHD to the point where conventional medicines are often no longer necessary.

PR7699AD **$16.95**

ADHD HANDBOOK FOR FAMILIES

A Guide to Communicating With Professionals

PAUL L. WEINGARTNER

This empowering book gives families practical concrete know how. It illustrates how to develop behavior modification plans, decide about medication, and how to work with clinical and education professionals for effective interventions.

CW173AD **$20.95**

1-2-3 MAGIC: EFFECTIVE DISCIPLINE FOR CHILDREN 2-12

New Revised 2nd Edition

THOMAS W. PHELAN, PH.D.

A how-to text designed to help adults learn how to handle difficult behavior, encourage good behavior, and manage the inevitable sidetrack of testing and manipulation - all in a manner that is fair, perfectly clear and not abusive.

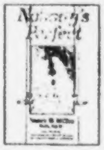
CM101GN BOOK	**$12.95**
CM130GN AUDIOBOOK	**$24.95**
CM120GN VIDEO	**$39.95**

PARENTING A CHILD WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER

JANE N. HANNAH

A practical and easy to read book that offers proven parenting approaches for helping children with ADHD improve their behavior.

PE167AD **$33.00**



NOBODY'S PERFECT

Living & Growing with Children Who Have Special Needs

N.B. MILLER, PH.D., M.S.W., ET AL

A guide to navigating the practical and emotional challenges of raising kids with disabilities.

PB0520D **$21.00**

ADHD ATTENTION-DEFICIT/HYPERACTIVITY DISORDER

What Every Parent Wants to Know

DAVID L. WODRICH, PH.D.

This exciting new second edition breaks down the complex issues surrounding ADHD today into easy to understand, non technical terms. Now parents and educators can quickly get the information they need to without taking the time to wade through heavy research. Includes: symptoms, diagnosis, medical interventions, instructional strategies and much more.

PB172AD **$21.95**

KEYS TO PARENTING A CHILD WITH ATTENTION DEFICIT DISORDER

Second Edition

BARRY E. MCNAMARA AND FRANCINE J. MCNAMARA

A guide for how to work with your child's school, effectively manage their behavior, and become a better advocate for them. Also includes answers to commonly asked questions.

BA2910AD **$7.95**

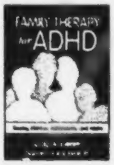
MEDICATION FOR ADD

An Up To Date Practical Resource for Parents, Adults, and Professionals

THOMAS W. PHELAN, PH.D.

This video answers some of the pressing questions everyone with ADD must face from what medication to use, to what will the side effects be.

CM150AD **$39.95**



FAMILY THERAPY FOR ADHD

Treating Children, Adolescents, and Adults

CRAIG E. EVERETT, SANDRA VOLGY EVERETT

A solid, eminently practical book that provides the guidance clinicians need to detect and treat ADHD in the family context. Especially helpful are the session by session assessments and treatment methods provided for children, adolescents, adults. It effectively demonstrates it's points through case studies throughout the book.

GL4383AD **$37.00**

BEYOND RITALIN

STEPHEN W. GARBER, PH.D., MARIANNE DANIELS GARBER, PH.D., ROBYN FREEDMAN SPIZMAN

Facts about medication and other strategies for helping children, adolescents, and adults with ADHD.

HC100AD **$13.50**

AUTISM

THE SIEGE

A Family's Journey into the World of an Autistic Child

CLARA CLAIBORNE PARK

At age two, Jessy Park was remote, withdrawn, unable to walk or talk, oddly content within the invisible walls that surrounded her. Doctors were baffled. The study of autism was still in its infancy. Jessy's family stepped in. Confronted with the child's refusal of life, all existential hesitations evaporate, They had no choice. They use every stratagem they could invent to assail her fortress, to beguile, entice, seduce her into the human condition. This is a powerfully moving book that is now regarded by many as a classic work as it charts a surprising journey of discovery as it records the challenges and rewards of the first eight years of Jessy's life.

LB0694AT **$15.95**

THINKING IN PICTURES
TEMPLE GRANDIN

THINKING IN PICTURES

My Life With Autism

TEMPLE GRANDIN WITH A FOREWORD BY OLIVER SACKS

The author is a gifted animal scientist who has designed one third of all the livestock-handling facilities in the US. She is also autistic, a woman who thinks, feels, and experiences the world in ways that are incomprehensible to the rest of us. In this unprecedented book, the author delivers a report form the country of autism. Writing from the dual perspectives of a scientist and an autistic person, we learn how the country is experienced by its inhabitants and how she managed to breach its boundaries to function in the outside world. What emerges is a document that sheds light on the riddle of our common identity.

RH118AT **$12.00**

CHILDREN WITH AUTISM

CHILDREN WITH AUTISM

Diagnosis and Interventions to Meet Their Needs

COLWYN TREVATHEN, KENNETH AITKEN, DESPINA PAPOUDI, AND JACQUELINE ROBARTS

This completely revised and substantially expanded edition embraces new developments in the treatment and diagnosis of autism. The authors illustrate how the complexity of autism means that many kinds of information are valuable and need to be utilized when treating a child with autism.

TF5550AT **$29.95**

SON RISE

The Miracle Continues

BARRY NEIL KAUFMAN

An inspiring journal of a family's successful effort to reach their autistic child. Includes stories of other families who have used the same approach to heal their special children.

OI089AM **$20.00**

Through the Eyes of Aliens

THROUGH THE EYES OF ALIENS

A Book About Autistic People

JASMINE LEE O'NEIL

This is a rich and positive description of how it feels to be autistic and how friends, family and the professionals that work with autistic people can be more sensitive to their needs. Written with a creative spin by an author who is autistic herself.

TF009AT **$24.95**

The world of the autistic child

THE WORLD OF THE AUTISTIC CHILD

A Guide for Families and Communities

BRYNA SIEGEL

Designed to guide parents, and professionals through the thickest of symptoms and labels. Explains the crucial importance of intensive early education and how to find the resources and help that are currently available.

OU201AT **$15.95**

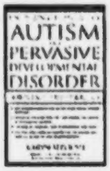
AUTISM: THE FACTS

Endorsed by the National Autistic Society

DR. SIMON BARON-COHEN AND DR. PATRICK BOLTON

Written mostly in a question and answer format this book is designed to provide families of children with autism scientific facts in a digestible form.

OU203AT **$19.95**



UNRAVELING THE MYSTERY OF AUTISM PERVASIVE DEVELOPMENTAL DISORDER

A Mother's Story of Research and Recovery

KARYN SEROUSSI

An inspiring and suspenseful chronicle of how one couple empowered themselves to challenge the medical establishment that promised no hope—and found a cure for their child. Here are the explanations and treatments they so carefully researched and discovered, a wealth of crucial tools and hands-on information that may help other parents reverse the effects of autism and PDD, including step-by-step instructions for the removal of dairy and gluten from the diet, special recipes and much more.

SS1643AT **$24.00**

EXITING NIRVANA

A Daughter's Life with Autism

CLARA CLAIBORNE PARK

The sequel to "The Siege", this book finds Jessy Park, now an adult, still struggling with language, with hypersensitivity's and obsessions, and with the social interactions that ordinary people take for granted but she cannot understand. With the help of family, teachers, and friends, Jessy has achieved more than her parents could have hoped for. This is a moving story about the making of a self and what it means to be human and a contributing active member of her family and community.

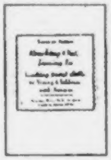
LB1178AT **$23.95**

EMERGENCE: LABELED AUTISTIC

TEMPLE GRANDIN AND MARGARET M. SCARIANO

Temple Grandin was labeled autistic as a child. In her own words, this story is about how she went from fear-gripped, autistic child to a successful professional and a world leader in her field. A remarkable and true story.

LB120AT **$12.99**



REACHING OUT, JOINING IN

Teaching Social Skills to Young Children with Autism

MARY JANE WEISS, PH.D., BCBA & SANDRA L. HARRIS PH.D.

Designed to show parents and professionals how to help young children with autism with one of their most challenging areas of development—Social behavior this book covers four broad topics. This book focuses on the following areas: play skills; the language of social skills; understanding another person's perspective; and using these skills in an inclusive classroom. This guide offers invaluable expertise and easy to understand activities parents and teachers can practice at home or at school to help kids with autism in preschool through elementary schools become more socially adept.

WB7240AT **$16.95**

THE ULTIMATE STRANGER

THE ULTIMATE STRANGER

The Autistic Child

CARL H. DELACATO

A new sensory approach to autism including an exciting breakthrough in treating an extremely difficult condition. Many suggestions are included for parents help them evaluate and to treat the problems of autism at home.

AT300AT **$15.00**

BEHAVIORAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM

A Manual for Parents and Professionals

CATHERINE MAURICE, ET AL.

A manual with a wealth of practical information for parents, professionals, and others concerned with helping children with autism. Contains stories of those who have benefited from behavioral interventions.

PE166AT **$39.00**

IAN'S WALK

A Story About Autism

LAURIE LEARS

A story for siblings of autistic children, to help provide them with an awareness of the challenges they and their families face. Grade 1-4.

AW120AT **$14.95**

RUSSELL IS EXTRA SPECIAL

A Book About Autism for Children

CHARLES A. AMENTA III, M.D.

Written to help the most important people, children, learn about autism by a father, who is also a physician, of an autistic child.

AP124AT **$11.95**

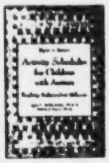
A Work In Progress

Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism

Ron Leaf and John McEachin

A superb collection of ideas and programs for building skills as well as strategies for dealing with challenging behaviors. It is a comprehensive guide presented in user friendly language so parents and professionals can easily understand and use this valuable resource.

DR6600AT **$42.95**



Activity Schedules for Children with Autism

Teaching Independent Behavior

Lynn E. McClannahan, PhD. & Patricia J. Krantz, PhD.

Detailed instructions and examples to help parents and professionals assess a child's readiness to use activity schedules; prepare an activity schedule; understand use of graduated guidance as a teaching tool; monitor progress and more.

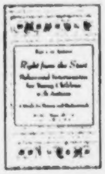
WB188AT **$14.95**

A Positive Approach to Autism

Stella Waterhouse

This fresh and positive book investigates how people with autism perceive the world, while discussing the symptoms behaviors and possible causes of the condition. Also presented are the potential compounding effects and interactions with hyperactivity and anxiety.

TF8088AT **$24.95**



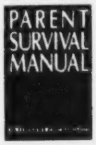
Right From The Start

Behavioral Intervention for Young Children With Autism

Sandra L. Harris, Ph.D. and Mary Jane Weiss, Ph.D.

A guide which describes Applied Behavior Analysis (ABA) and Intensive Behavioral Intervention (IBI)—one of the most successful, proven treatment and educational methods for young people with autism—to parents in an easy to read and understand language.

WB183AT **$14.95**



Parent Survival Manual

A Guide to Crisis Resolution in Autism and Related Developmental Disorders

Edited by E. Schopler

Includes many practical suggestions for dealing with the day to day challenges of life with a child who has autism.

PL1490D **$39.50**

Facing Autism

Giving Parents Reason for Hope and Guidance For Help

Lynn M. Hamilton

Discover ten things you can do to begin battling your child's autism right now in this amazing text. Explore and examine the treatment of choice for most parents, Applies Behavior Analysis, and find information on cutting edge biomedical treatments such as secretion and immunotherapy.

WP2627AT **$14.95**

BEHAVIOR

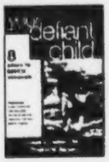
Defiant Children: A Clinician's Manual for Assessment and Parent Training

Second Edition

Russell A. Barkley, Ph.D.

Updating and expanding the first edition, this remarkably clear and effective manual includes, in a single spiral bound volume, a thorough clinical guide to Dr. Barkley's 10 session parent training program, a fully rewritten assessment section that incorporates DSM IV diagnostic criteria, and reproducible parent handouts reinforcing each step of the program. Special features include: Overview of program's purpose and goals and extensive outcome documentation, step by step instructions for each parent training session, A new home based reward system to improve school behavior plus much more.

GL1236BM	**$35.95**
GL2267BM-SPANISH	**$35.95**



Your Defiant Child

8 Steps to Better Behavior

Russell A. Barkley, Ph.D. and Christine M. Benton

Every child has "ornery" moments, but more that 1 in 20 American children exhibit behavioral problems that are out of control. If you are struggling with an unyielding or combative child, this book offers you the understanding and guidance you need. The book contains a clear explanation of what causes defiance, when it becomes a problem, and how it can be resolved. The comprehensive eight step program emphasizes consistency and cooperation, promotes changes through a system of praise, rewards, and mild punishment. Filled with practical charts, questionnaires, and check list which help you get your child's behavior back on track.

GP3212GN **$15.95**

Defiant Teens

A Clinician's Manual for Assessment and Family Intervention

Russell A. Barkley, Gwenyth H. Edwards, and Arthur Robin

This manual presents an 18 step program designed both to teach parents the skills they need to manage difficult adolescent behavior and to improve family relationships overall. Steps 1 through 9 modify the approach presented in "Defiant Children" to focus on developmental concerns of adolescence. Steps 10 through 18 are conducted with parents and their teenagers together, utilizing a family therapy model developed by Arthur L. Robin and Sharon Foster. Clinicians are shown how to help all family members learn to negotiate, communicate, and problem solve more effectively, while facilitating adolescents' individuation and autonomy. Reproducible forms enable clinicians to gauge nature, diversity, and severity of conflicts; assess for oppositional defiant disorder; and evaluate parental psychological adjustment. Also reproducible handouts for families to reinforce session ideas and concepts.

GL4405BM **$35.00**

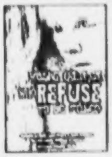
1-2-3 Magic: Effective Discipline for Children 2-12

Second Edition

Thomas W. Phelan, Ph.

A How To text designed to help adults know how to handle difficult behavior, encourage good behavior, and manage the inevitable sidetrack of testing and manipulation — all in a manner that is fair, perfectly clear and not abusive.

CM152AD (Spanish)	**$9.95**
CM101GN (English)	**$12.95**



Raising Children Who Refuse to Be Raised

Dave Ziegler, Ph.D.

This book is for both parents and professionals who are involved with the care of children who have severe emotional or behavioral disturbances as the result of abuse or neglect. The three major sections cover: Emotional disturbances, Where it all Begins, Behavioral Disturbances: There is More than Meets the Eye, and lastly Advanced parenting Skills and Challenges. The 12 chapters contain detailed discussions of emotional or behavioral disorders, their causes and possibilities for treatment.

AC8727BN **$19.99**

More 1-2-3 Magic

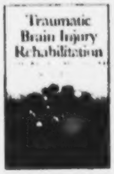
Encouraging Good Behavior, Independence and Self Esteem

Thomas W. Phelan, Ph.D.

In addition to controlling difficult behavior, parents need to know how to encourage good behavior so they can enjoy their children and relate to them with warmth and affection. This video covers 3 parental qualities that foster competence in kids, How to encourage and respect your child's growing independence; 10 strategies for building self-esteem, How to get your kids to pick up after themselves and much more.

CM0102AD **$39.95**

BRAIN INJURY



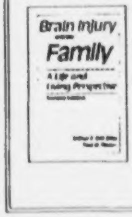
Traumatic Brain Injury Rehabilitation

Children and Adolescents

Mark Ylvisaker

This new Second Edition covers all aspects of rehabilitation, and emphasizes collaborative efforts across disciplines, areas of functioning and settings. It focuses on both intermediate and long term issues.

BH109BI **$65.00**



Brain Injury And The Family

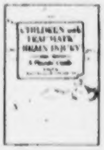
A Life And Living Perspective

A.E. Dell Orto & P.W. Power

This new edition focuses both on how the family can adjust and survive the trauma related to head injury, as well as become a partner in the treatment, rehabilitation, and adaptation process.

GR1170O **$44.95**

BRAIN INJURY



Children with Traumatic Brain Injury
A Parents' Guide
Lisa Schoenbrodt, Ed.D, CCC-SLP

When a child sustains a traumatic brain injury, there are often immediate medical and therapeutic needs as well as long term effects on behavioral, cognitive, and physical skills. This book is designed as a comprehensive reference that will provide parents with the support and information they need to cope and help their child recover. Included are topics such as: diagnosis, rehabilitation and medical concerns, coping and adjustment, effects on behavior and management strategies plus much more.

WB9999BI **$17.95**

Before and After Zachariah
A True Story About A Family and A Different Kind of Courage
Fern Kupfer

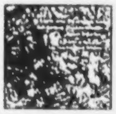
A gripping autobiographical tale of a parent's heart wrenching decision on how to care for their newborn brain damaged son. Here we learn there are alternatives and that they, too, are honorable.

AP111GN **$14.00**

Work Worth Doing
Advances in Brain Injury Rehabilitation
Brian T. McMahon Ph. D. and Linda R. Shaw Ph.D.

An important and possibly controversial book of issues and methods that address the full spectrum of vocational rehabilitation activities. Independent living; treatment generalization; criteria for evaluating TBI facilities; family involvement and more.

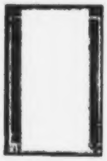
GR1100D **$57.95**



Signs and Strategies for Educating Students with Brain Injuries
A Practical Guide for Teachers and Schools
G. Wolcott, M. Ed., M. Lash, M.S.W., & S. Pearson, M.A.

Filled with useful guidelines, practical tips, and intervention strategies that enable parents and teachers to better understand the educational needs of children and adolescents with brain injuries.

HI1760D **$24.95**



Childhood Traumatic Brain Injury
Diagnosis, Assessment and Intervention
Erin D. Bigler, Elaine Clark, and Janet E. Farmer

A well balanced and comprehensive treatise on childhood traumatic brain injury. Covers a wide variety of issues surrounding brain injury in children from social expectations to assessment of skills.

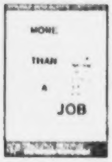
PE1436I **$38.00**

CAREER DEVELOPMENTS

Keys to the Workplace
Skills and Supports for People with Disabilities
Michael J. Callahan and J. Bradley Garner

A unique resource on employment which introduces an easy to implement process for developing and carrying out individualized effective job search plans. A testimony and a tool for ensuring appropriate, self directed employment for people with disabilities.

PB2762WP **$29.95**



More than a Job
Securing Satisfying Careers for People with Disabilities
Paul Wehman & John Kregel

Focuses on the individual in their search for competitive employment. Strategies that use vocational training, supported employment, and assistive technologies are just some of the key methods explored. Emphasizes consumer choice in selecting a job.

PB1430D **$34.95**

CEREBRAL PALSY

I Wish...
Dreams & Realities of Parenting a Special Needs Child
Kate D. McAnaney

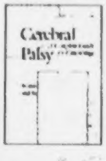
A true story about conflict, courage and creative solutions. Without belligerence or self pity, this little book has had the power to bring hope, encouragement and perspective to many. This book achieves that power because its author speaks simply, plainly and eloquently from direct experience. There is purity in this matter-of-fact witness which shows itself as well in many books which are far more widely known. But to the reader it simple means,"This book can be useful"

SN074CP **$12.95**

Keys to parenting a Child with Cerebral Palsy
Jane Faulkner Leonard, P.T.,M.S.H.P.; Sherri L. Cadenhead, M.S.P.T., P.C.S; Margaret E. Myers, O.T.R.

Raising a Child with cerebral palsy can be a challenging but enlightening journey. Practical resource for parents who wish to understand cerebral palsy, deal with their feelings, balance family relationships and plan for their child's future.

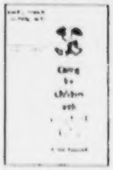
BA101CP **$6.95**



Cerebral Palsy
A Complete Guide for Caregiving
F. Miller, M.D. & S. Bachrach, M.D

Offering sound professional advise with a caring commitment to do what's best for a child with Cerebral Palsy.

MI151CP **$19.95**



Caring for Children with Cerebral Palsy
A Team Approach
John P. Dormans, MD; Louis Pellegrino MD

Provides detailed information on a multitude of issues, including definitions, diagnosis, prognosis, health maintenance, preventive care, orthopedics, feeding and nutrition, daily living skills, family, school, and community roles and much more.

PB149CP **$43.95**

On Being Sarah
Elizabeth Helfman

Sarah has the same wishes any girl has: meet people, make friends, see the world. An excellent story about a girl overcoming her disability, cerebral palsy, and the friends she makes along the way.

AW125CP **$ 14.95**

Cerebral Palsy
Merlin J. Mecham

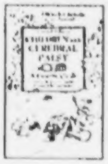
A concise and comprehensive examination of a cluster of developmental motor speech disorders that have come to be classified under cerebral palsy. Provides up to date coverage of clinical problems that are faced.

PE180CP **$31.00**

Stretching Ourselves
Kids With Cerebral Palsy
Alden R. Carter with photographs by Carol S. Carter

An excellent book that illustrates just how parents and children with cerebral palsy can stretch themselves out to be active in games and other activities together.

AW6379YP **$14.95**

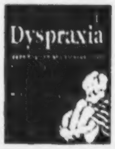


Children with Cerebral Palsy
A Parent's Guide: Second Edition
Edited by E. Geralis

Considered to be the first book that families should read , now completely updated. Provides comprehensive coverage of the concerns and issues central to giving children a head start on achieving independence and lead rewarding lives.

WB012PD **$16.95**

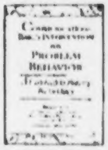
COMMUNICATION



Developmental Dyspraxia: Identification and Intervention
A Manual for Parents and Professionals
Madeleine Portwood

This text is designed to provide sufficient information to parents, teachers and professionals so they have the confidence to diagnose and assess dyspraxia. It also offers an intervention program which will significantly improve the cognitive functioning of the child or teenager.

TF1200D **$26.95**



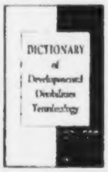
Communication Based Intervention for Problem Behavior
A User's Guide for Producing Positive Change
Edward G. Carr, Len Levin, Gene McConnachie, Jane I. Carlson, Duane C. Kemp, and Christopher E. Smith
Consolidating years of important research and personal skill, this step by step guide details innovative methods for managing episodes of problem behavior, conducting initial and ongoing functional assessments, selecting and teaching forms of communication, and working toward maintenance and generalization. This is an indispensible resource to help individuals with disabilities curtail problem behavior and gain greater independence in the community.

Marvelous Mouth Music
Songs for Speech Therapy and Beyond
Suzanne Evans Morris, Ph.D.
An excellent use of folk music for the development of language skills. Helps to create an accelerated learning environment as well as teaching children skills to cope with oral disorders. Includes audio tape and book.
BC200ST **$22.95**

Interventions for Students with Leaning Disabilities
A Meta-Analysis of Treatment Outcomes
H. Lee Swanson with Maureen Hoskyn and Carole Lee
Funded through a grant from the U. S. Department of Education, this text provides a technical comprehensive report on approximately 30 years of intervention research for students with disabilities. Condensed into more that 700 pages and following a typical research organizational format the reader is provided with a justification for the synthesis, detailed results and discussion of the most important findings.
GL050LD **$ 79.00**

DEVELOPMENTAL DISABILITIES

Music Therapy for the Developmentally Disabled
Edith Hillman Boxill
A complete source book filled with practical guidelines, case samples, and step by step instructions that enable you to bring about dramatic improvements in children with developmental disabilities through the miracle of music.
PE150DD **$40.00**

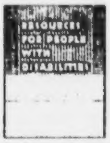


Dictionary of Developmental Disabilities Terminology
Pasquale J. Accardo & Barbara Y. Whitman
This valuable dictionary is an essential tool for anyone involved in caring for a child with developmental disabilities. More than 3000 terms with thorough and easy to understand definitions including Anomia, Down syndrome, Cerebral Palsy, and much more.
PB150DD **$35.95**

Teaching Developmentally Disabled Children
Ivar Lovaas
A clear and concise instructional program for teachers and parents that shows how to help children who are developmentally disabled function more normally at home, at school, and in the community.
PE141DD **$36.00**

Best and Promising Practices In Developmental Disabilities
Alan Hilton and Ravic Ringlaben
An excellent reference guide for implementing practices in settings that serve students with developmental disabilities.
PE171DD **$46.00**

DIRECTORIES



Resources for People with Disabilities
A National Directory
Ferguson Publishing
Elizabeth H. Oakes and John Bradford
A comprehensive 2-volume directory with more than 8,100 entries containing valuable information to help people with disabilities realize their goals. Indexed by state, by type of disability and by name of organization or association. 1026 pages
FP3092DI **$89.95**

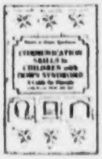
Children with Disabilities
A Medical Primer
M.L. Batshaw, M.D. & Y.M. Perret, M.A
Revised Fourth Edition, for parents and professionals. Over 200 detailed illustrations, an extensive glossary, and a section on syndromes.
PB071DD **$59.95**

DOWN SYNDROME

Russ and the Almost Perfect Day

Russ and the Almost Perfect Day
Janet Elizabeth Rickert, Photographs by Pete McGahan
This storybook focuses on how much Russ is like other kids his age rather than on the fact he has Down syndrome. Very useful in early childhood and elementary classrooms or in the home where parents want their children to appreciate people for their humanity and recognize that everyone has common similarities and unique differences but are of equal value.
WB7186DS **$14.95**

Life As We Know It
A Father, A Family, and an Exceptional Child
Michael Be'rube'
The author, a literary critic, tells what it has been like raising his son, a lively, loving, mischievous boy who also has Down Syndrome. A tale of medical procedures insurance guidelines, policies and challenges encountered as he viewed him as a person.
RN112DS **$14.00**



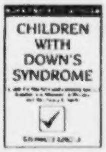
Communication Skills in Children with Down Syndrome
A Guide for Parents
L. Kumin, Ph.D.,CCC-SLP
Provides parents with a wealth of information about speech and language development in children with Down syndrome.
WB031DS **$14.95**

A Promising Future Together
A Guide for New Parents of Children with Down Syndrome
The diagnosis of a baby with Down syndrome is not as "life changing" as the fact that you have a new baby. It is important to remember that your baby is just like any other baby in most ways. Babies need to be fed, held and to be loved. There will be challenges and also many many joys. This video tells the tale of a family and how they cope with Down syndrome and their newborn.
ND001DS **$21.95**

Teaching the Infant with Down Syndrome
A Guide for Parents and Professionals
M.J. Hanson, Ph.D.
The latest information on teaching activities for infants, resources for parents, medical facts about Down syndrome and tips for parents on how best to help and enjoy their babies.
PE048DS **$31.00**

Fine Motor Skills in Children With Down Syndrome
Maryanne Bruni, BSc OT(C)
Written for parents, health professionals, and teachers, for use as a practical and accessible guide to developing and understanding fine motor skills in children with Down syndrome from infancy to early adolescence. Includes activities and instructions.
WB186DS **$16.95**

Schooling Children with Down Syndrome
Toward an Understanding of Possibility
Christopher Kliewer
This book traces the history of community banishment inflicted on people with Down syndrome, and addresses issues such as literacy and language. Concludes that students with Down syndrome are inherently valuable to the classroom community and calls for the inclusion of all into the learning environment.
TC100DS **$29.95**

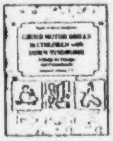


Children With Down's Syndrome
A Guide For Teachers and Learning Support Assistants in Mainstream Primary and Secondary Schools
Stephanie Lorenz
This practical handbook offers advice on strategies for meeting the special educational needs of children with Down syndrome in mainstream schools. The aim is to increase the confidence of support assistants and others in providing a quality education for their pupils.
TF130DS **$23.95**

DOWN SYNDROME

Babies with Down Syndrome
A New Parents' Guide
Second Edition
Edited by K. Stray Gundersen
A newly revised complete and compassionate guide, written by doctors, nurses, educators, lawyers, and parents.
WB156DS-english **$15.95**
WB178DS-spanish **$15.95**

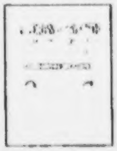
Count Us In
Growing Up with Down Syndrome
J. Kingsley & M. Levitz
Mitchell Levitz and Jason Kingsley share their innermost thoughts, feelings, hopes and dreams, their lifelong friendship and their experiences of growing up with Down syndrome.
HB073DS **$9.95**



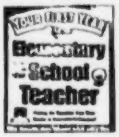
Gross Motor Skills in Children with Down Syndrome
A Guide for Parents and Professionals
Patricia C. Winders, P.T.
A how-to guide for meeting the challenges Down syndrome presents for gross motor development, coordination of large muscle groups and the sequencing of movements in young children. This book provides guidance for parents of children ages birth through 6 years.
WB171DS **$16.95**

Time to Begin
Early Education for Children with Down syndrome
Valentine Dmitriev
This book is intended as a reference, as a textbook, and as a manual for parents, teachers, and other professionals who wish to accelerate the development of children with Down syndrome or with other developmental delays. The reader is given practical and specific techniques to use in a program of early intervention. Exercises and activities are based upon what is currently known about child development.
PE8605DS **$33.00**

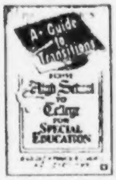
EDUCATION



Children and Youth Assisted by Medical Technology in Educational Settings
Guidelines for Care
Stephanie Porter, M.S.N., R.N., Marilynn Haynie, M. D.
Timaree Bierle, B.S.N., R.N., Terry Heintz Caldwell, Ed.D. and Judith S. Palfrey, M.D.
A collaborative, interactive process involving parents, students, teachers, lawyers, nurses and doctors has created this new Second Edition that reflects the reality in schools, the tension, the dilemmas, the weakness, and the strengths.
PB142ED **$53.00**

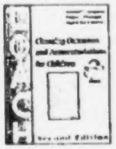


Your First Year as an Elementary School Teacher
Lynne Rominger, Karen Heisinger, Ed.D. & Natalie Elkin
Making the Transition from Total Novice to Successful Professional
Many begin teaching because of a desire to make a difference. But faced with the everyday challenges of the classroom, this idealism is often lost. The fact is, teaching is not easy. This book provides practical solutions to the most common and difficult issues of teaching. The text is designed to help you create an atmosphere of cooperation, learning, and respect within your classroom.
PR9683ED **$18.95**



A+ Guide to Transitions from High School to College for Special Education
A Guide for Parents & Students; A Tool for Educators
Grace M. Hanlon, MS
A "college prep" video for parents and students. Teachers, parents, and school administrators describe the transition processes and offer their best advice for having a positive experience. Some of the topics covered include: Identifying Transition Goals in preparation for college; The Role of School Counselors and Learning Consultants; Preparation of a Student Portfolio and Transition Goals in the IEP; The Law, ADA Rule 504; A Check List for Interviewing Colleges and much more.
EV6858ED **$49.95**

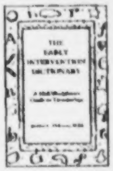
How to Help Your Child Succeed in School
Strategies and guidance for parents of children with ADHD and/or Learning Disabilities
Sandra Rief
The focus is on the key for success — a strong partnership in education between home and school. View real parents and their children cover topics that include: reading, writing and math skill development, building of organization and study skills.
ER101AD (video) **$46.00**



C. O. A. C. H. Choosing Outcomes and Accommodations for Children
A Guide to Educational Planning for Students with Disabilities
Michael F. Giangreco, Chigee J. Cloninger
This user friendly popular planning tool provides detailed explanations, explicit instructions, "helpful hints" for each step, and tabs for pinpointing information. It contains established, practical, and field tested methods for both special and general educators, relayed service providers, school administrators, and parents who work toward creating a meaningful IEP for each students.
PB3238ED **$39.95**

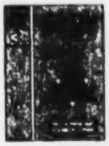
Meeting With Success
Tips For Of Successful IEP, Setting The Standard For Excellence
Jerome J. Schultz, PhD.
A useful tool to help prepare both professionals and parents for the IEP process. It focuses on preparation, teamwork, and collaboration in the process
LD202ED **$79.95**

EARLY INTERVENTION



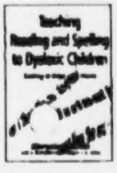
The Early Intervention Dictionary
A Multi-Disciplinary Guide to Terminology
J.G. Coleman, M.Ed.
Defines and clarifies terms used by the many different medical, therapeutic, and educational professionals who provide intervention services.
WB030EI **$17.95**

DYSLEXIA

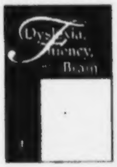


Dyslexia
A Parents' and Teachers' Guide
Trevor Payne and Elizabeth Turner
This book is a handy practical guide to the educational difficulties encountered by children with dyslexia. It examines methods to help them improve their reading skills, and relays the message in plain language with no technical jargon.
TF200DY **$26.95**

The Worst Speller in Jr. High
Caroline Janover
A fast paced fictional story about romance, self-esteem, and living with a learning difference through the eyes of Katie, a junior high school student.
FS100DY **$4.95**



Teaching Reading and Spelling to Dyslexic Children
Getting to Grips with Words
Rita Jordan and Glenys Jones
A friendly book that helps both educators and parents teach dyslexic children to read and spell. It focuses on two original charts which present the main spelling patterns and rules of English.
TF210DY **$29.95**



Dyslexia, Fluency, and the Brain
Maryanne Wolf
Consider the time it takes for the brain to process written language. What impact does the brain's processing time have on reading, development? What are the relationships among processing time, reading fluency, and dyslexia? Can time and fluency related problems be changed? How should intervention be designed to address the issue? This monumental resource presents evidence indicating that many dyslexic children have a second core deficit in rate of processing linguistic differences in multiple areas. This book has been constructed to bring several levels of evidence and types of research to bear on these questions.
YP2602DY **$30.00**

EPILEPSY

Epilepsy: The Facts

Second Edition

Anthony Hopkins
and Richard Appleton

This excellent book is designed to present the facts about every aspect of epilepsy in a clear and concise manner. Written by a neurologist, it presents a clear definition of epilepsy, the different types of seizures associated with the disorder, the medical and surgical therapies used, as well as providing practical points on living with epilepsy.

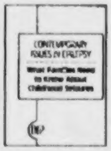
OU5489EP $19.95

Lee, The Rabbit With Epilepsy

Deborah M. Moss

A reassuring tale for young children with epilepsy. The story follows Lee from her first seizure to the doctor's office, and then home with new medication to control her seizure. Ages 4-8

WB182EP $12.95



Contemporary Issues in Epilepsy

What Families Need to Know About Childhood Seizures

In edition to the monograph "The Changing Nature of Epilepsy: New Patterns Of Care For the 21st Century", this issue is devoted to a more personal topic: What parents need to know about childhood seizures. The focus is on what is currently known including: prognosis; communication on the subject within the family and externally to friends and caregivers; first aid for seizures; genetics and what we know today, plus much more. Intertwined with these articles by medical specialists are articles focusing on families of children with epilepsy, providing first-hand experience from the perspective of a parent. In addition there is an extensive resource section, identifying organizations as well as published, video and Internet sources of information for parents and children.

EP550EP $5.95

GENERAL

Neuroimaging

A Window To The Neurological Foundations of Learning and Behavior in Children

G. Reid Lyon, Judith M. Rumsey

Explores the application of anatomical and functional neuroimaging techniques and procedures to the understanding of specific medical conditions and developmental disabilities in children. Includes two chapters covering the basic biological and methodological concepts needed to understand neuroimaging procedures.

PB2568NI $49.95

Uncommon Fathers

Reflections on Raising a Child with a Disability

Edited by D.J. Meyer

A compelling collection of essays by fathers who were asked to reflect and write about the life-altering experiences of having a child with a disability.

WB1240D $14.95

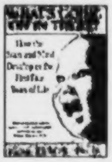
Kids with Celiac Disease

A Family Guide to Raising Happy Healthy Gluten-Free Children

Donna Korn

The first practical survival guide for families of children and teenagers with this life long digestive disorder. This guide covers everything from medical issues to shopping, food preparation, menu and snack ideas, and from eating outside the home to behavior management. An extensive resource section offers useful contacts for products and services. The information provided will save parents hours of unnecessary anguish and frustration and will help them deal with their challenges in a positive, constructive manner.

WB7216CD $17.95



What's Going On In There?

How the Brain and Mind Develop in the First Five Years of Life

Lisa Eliot, PhD

This thought provoking exploration of the questions critical to every prospective parent is a must read for every parent to be. Brilliantly blending cutting edge science with a mother's own insight and wisdom, this book shows parents and caregivers the innumerable ways which they can actually help their children grow better brains.

BD8252GN $16.95

YES
YOU
CAN!
Mark Nagler, Ph.D.

Yes You Can!

A Guide for Parents of Children with Disabilities

Mark Nagler, Ph.D.

Parents and caregivers are provided with advice and support for maintaining the quality of family, personal and social life while maximizing the rehabilitative potential of the child with special needs.

GD02000 $13.95

Play Therapy with Children in Crisis

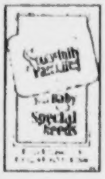
Play Therapy With Children In Crisis

Individual, Group, and Family Treatment

Nancy Boyd Webb

Filled to the brim with information, insight, and information. Calls upon the experiences found in actual play therapy sessions to bring children's voices and play behaviors to life, affording insight into their experiences and emotions.

GL4855MH $46.00



Successfully Parenting Your Baby With Special Needs

Early Intervention for Ages Birth to Three

Grace Hanlon

Discovering your baby has a special need can be a very traumatic experience. This video is designed to give parents hope and support through enlightening them to the wonderful benefits of Early Intervention. It describes a process designed for young children ages birth to three with unique needs. Includes Individualized Family Service Plan and much more.

EVI74EI $49.95

Happy
Family

Build A Happy Family

A Positive Parenting Tool Kit on "How to be the Parent You Want to be When you Just Don't Have the Time"

Frank J. Doberman, Ph.D.

This book introduces the twelve basis skills of positive parenting and also show parents how to find the time to use these tools while having the energy to become the parents they want to be with happy, healthy and thoughtful children.

WC100GN $15.00

no
ordinary
move

No Ordinary Move

Linda Bidabe with Chris Voll

The author, a trail blazing California teacher who set beanbag kids on their feet because she believed they could walk, reveals the secret to her success and the source of the passion that drives her. This book is a triumphant story of renouncing victimhood, reclaiming human dignity, and risking everything to see caged hearts and minds set free.

PL9153GN $24.00

Someone Special Just Like You

Tricia Brown and Fran Ortiz

Upbeat black and white photographs with simple large type text showing pre-school children actively playing and learning, alone with teachers, and with their peers. Demonstrates common needs for physical affection, community, skills and independence.

NH104GN $6.95

Steps to Independence

Teaching Everyday Skills to Children With Special Needs

Third Edition

Bruce L. Baker
& Alan J. Brightman

A step by step guide to help parents teach essential life skills to their children. Includes behavioral problems management, toilet training, home care skills, chores and much more.

PB151GN $28.00

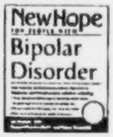
After Your Child's Diagnosis

A Practical Guide for Families Raising Children With Disabilities

Cathy Linn Binstock

This book offers practical assistance in the way of resources, references, and options available when seeking treatments after a child has been diagnosed. Included are both positive and negative experiences to help one anticipate and cope.

EM100GN $21.95



New Hope for People with Bipolar Disorder

Jan A Fawcett, MD; Bernard Golden, Ph.D., and Nancy Rosenfeld

This book dispels the myths and fears surrounding bipolar disorder. It offers compassionate, practical, and immediate guidance for anyone affected by this disorder. Presented by known professionals are: Causes, symptoms, and patterns of bipolar disorder; new medications; latest psychiatric findings; cutting edge treatment models and much more.

PR0088BD $18.95

GENERAL

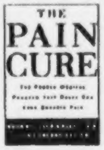
WHY DON'T THEY LIKE ME?

Helping Your Child Make and Keep Friends

SUSAN M. SHERIDAN, PHD

Making friends and getting along with others is a big part of a child's life. The many examples, how to steps, scripted role plays, and innovative Social Skills Cards will enable parents to teach their children how to make and keep friends.

SW1244GN **$18.50**



THE PAIN CURE

The Proven Medical Program that Helps End Your Chronic Pain

DHARMA SINGH KHALSA, MD WITH CAMERON STAUTH

An innovative four level approach to pain management that combines aspects from nutrition, physical therapy, medication, and mental and spiritual wellness.

TW5865IN **$14.95**

YOUR PREMATURE BABY AND CHILD

Helpful Answers and Advice for Parents

AMY E. TRACY AND DIANE I. MARONEY

This illustrated guide, written by experienced preemie mothers and medical professionals can help parents as they are confronted by the unique challenges by little ones who seem as fragile as they are precious. The topics covered include: Homecoming, Medical Issues, Feeding Concerns, Growing and Thriving, School Years, Family Matters, and much more.

GP5061PB **$14.95**

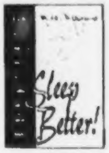
DELICATE THREADS

Friendships between Children With and Without Special Needs in Inclusive Settings

DEBBIE STAUB, PH.D.

A view of the social lives of children with and without disabilities. Reveals characteristics and patterns of these complex relationships and provides useful suggestions for families and educators interested in supporting these relationships.

WB185GN **$16.95**



SLEEP BETTER

A Guide For Improving Sleep for Children With Special Needs

V. MARK DURAND, PHD.

This text begins with a discussion of sleep followed by a description of a range of sleep problems and includes a step by step interview that will help you identify the type of problems being encountered. Includes treatment options covering bed wetting, sleep walking, insomnia and much more.

PB166GN **$23.95**

PAY ATTENTION SLOSH!

MARK SMITH

Joe doesn't know why he can't sit still or pay attention, that is until someone explained to him he had ADD/HD.

AW126AD **$12.95**

BULLY PROOFING YOUR CHILD

A Parent's Guide

CARLA GARRITY, PHD, MITCHELL BARIS, PHD, AND WILLIAM PORTER, PHD

This step by step guide is designed to help children develop and effective personalized strategy for dealing with bullies. Parents now will be able to keep their child safe, eliminate a sense of helplessness in their child, and equip their children with valuable problem solving and social skills.

SW247XGN **$12.95**

WHEN YOUR CHILD HAS A DISABILITY

A Complete Sourcebook of Daily and Medical Care

MARK L. BATSHAW, MD

This completely revised and expanded edition is designed to help parents meet the demands of raising a child. Answers questions and provides advice on pediatric care; behavior; nutrition and feeding; medication; child development and much more. Also includes detailed coverage of the daily and long-term care requirements of specific disabilities plus an extensive list of resources.

PB4722GN **$22.95**

CHILDREN WITH FRAGILE X SYNDROME

A Parent's Guide

EDITED BY JANE DIXON WEBER

Written by leading professionals in the field as well as experienced parents, this guide is both supportive and authoritative. It is filled with up-to-date information that helps families adjust to, and understand their child's strengths and weaknesses. It is an essential book for parents, teachers and professionals working with children who have this condition.

WB9778GN **$17.95**

IS MY CHILD OK?

When Behavior Is A Problem, When It's Not, and When to Seek Help

HENRY A. PAUL, MD

Every parent has asked this question at one time or another. This wise and compassionate guide offers reassuring words for worried parents as well as concrete ways to spot problems between a normal stage of development…and a true problem. This one step reference book tells parents what is normal, what is not, and where to get help.

RH8878GN **$13.00**

GRIEF DANCERS: A JOURNEY INTO THE DEPTHS OF THE SOUL

SUSAN ZIMMERMAN

A mother's story of achieving unconditional love and acceptance of her handicapped child for who she is, and not what she is.

NP1000D **$14.95**

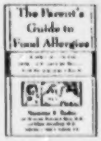
DIFFERENCES IN COMMON

Straight Talk on Mental Retardation, Down Syndrome, and Life

M. TRAINER

Marilyn Trainer draws on her experience with candor and humor, as a mother of a child with Down syndrome, now in his twenties. A fresh outlook on the challenges, hopes and fears of family life.

WB009MR **$14.95**

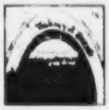


THE PARENT'S GUIDE TO FOOD ALLERGIES

MARIANNE S. BARBER

Clear And Complete Advice From The Experts On Raising Your Food-Allergic Child

HH6004FA **$15.00**



TAKING A BREAK WITH KIDS FIRST

RACHEL WRIGHT AND MAUREEN BRADY

Designed to promote rest and relaxation in children of various ages and abilities. This CD combines Native American flute music with a soothing dialogue that incorporates visualization techniques. Has been found to assist children in reducing stress and in promoting an inner calmness. Can be used in schools, hospitals and clinics.

KF4020GN **$19.99**

AFTER THE TEARS

Parents Talk about Raising a Child with a Disability

ROBIN SIMONS

This book is the story of parents who have struggled, learned and grown in the years since their children were born. All of them felt an initial anguish on learning of their child's disability. All have come a long way since those initial tears. They share their stories with you to give you the benefit of their experiences, to let you know you're not alone, and to offer you encouragement in growing with and loving your child.

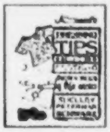
HB9006GN **$11.00**

THE BRAND NEW KID

KATIE COURIC WITH ILLUSTRATIONS BY MARJORIE PRICEMAN

Everyone remembers feeling excited and nervous each fall on the first day of school, especially Lazlo S. Gasky who is the new kid at Brookhaven School. Join Lazlo and his classmates as they learn a valuable lesson about accepting people who are different.

BO0300FY **$15.95**



DRESSING TIPS AND CLOTHING RESOURCES FOR MAKING LIFE EASIER

SHELLEY PETERMAN SCHWARZ

A large print 138 page book that includes how and where to shop for special clothing or dressing devices. In addition to providing a directory of more than 100 business that offer specially designed or adapted clothing for people of all ages and physical disabilities the reader is provided with tips on choosing the right clothing, how to modify clothing already own and ways to make dressing easier.

AC1199GN **$19.95**

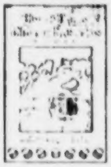
9 MYTHS THAT DAMAGE A CHILD'S CONFIDENCE

What Parents Think, What Children Say, What Professionals Observe

PAT HOLT

This brief clear book draws information from kids, parents and professionals to help moms and dads do their best for their children. This valuable book is written by someone who has been there.

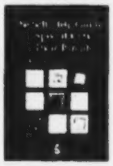
WP5915GN **$8.99**



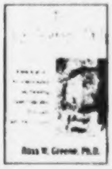
Distant Drums, Different Drummers
A guide for young people with ADHD
Barbara D. Ingersoll, Ph. D.
A view that offers children and adolescents struggling with ADHD the opportunity to see them selves in a positive light due to their penchant for novelty and exploration and boundless energy.
CP100AD **$15.95**

The Shy Child
Helping Children Triumph Over Shyness
Ward K. Swallow
This authoritative interactive guide focuses on the problems of shyness and provides parents and children with pragmatic step-by-step solutions. It will help you achieve wonderful results such as stronger warmer relationships with family and friends, and a child who looks confidently to the future.
TW4990GN **$13.95**

Putting Children First
Hanna McDonogh
and Christina Bartha
Besieged by multiple emotional, financial, legal, and practical stresses, divorcing parents are at heart often deeply worried and guilty about their children. This book provides ways for parents to develop the skills necessary to help their children in this period such as understanding grieving, relationships, mediation, court proceedings, and much more.
UT0642GN **$17.95**



The Self-Help Guide for Special Kids and Their Parents
Joan Matthews and James Williams
Covering everything from eye sensitivity, to knowing how far away to stand from other people, to being polite when someone is crying, this autobiographical story describes the problems that any special person may face and the solutions which they have found to work successfully.
TF9149GN **$17.95**



The Explosive Child
A New Approach for Understanding and Parenting Easily Frustrated, "Chronically Inflexible" Children
Ross W. Greene, Ph.D.
Practical comprehensive approach aimed at decreasing adversarial interactions between parents and children, reducing family hostility and improving children's capacities for flexibility, frustration tolerance, communication and self-regulation.
HC300GN **$24.00**

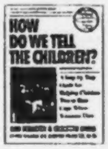
How to Keep Your Kids from Driving You Crazy
Paula Stone Bender, Ph.D.
A hands on and extensively tested "Behavior Game" that let you use positive reinforcement to achieve the changes you want. Easy to use charts, checklists, and worksheets enable you to tailor the program to met your family's specific needs.
JW123GN **$14.95**

GRIEVING

Remembering With Love
Messages of Hope for the First Year of Grieving and Beyond
Elizabeth Levang, PhD.
and Sherokee Ilse
An affirming gift for those grieving the loss of a loved one, offering compassion, comfort and guidance with over three hundred short pieces written by those who have been there.
FP0400E **$11.95**

The Worst Loss
How Families Heal from the Death of a Child
Barbara D. Rosof
How do families survive the worst loss? What helps people heal? What barriers are there to healing, and what will break down those barriers?
HH0300D **$16.00**

Gentle Willow
A Story for Children About Dying
Joyce C. Mills, Ph.D.
This comforting story will help children deal with the death of friends, a family member, or even pets. It is a loving tender tale that addresses our feelings of sadness, love, disbelief, and anger. This profound story is ultimately one of joy and hope.
AP133GN **$11.95**

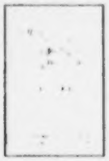


How Do We Tell The Children
A Step By Step Guide for Helping Children Two to Teen Cope When Someone Dies
Dan Schaefer and Christine Lyons
Drawing on more than three decades of experience helping families in crises the author provides valuable information for adults to help them understand what children are capable of understanding about the loss of a loved one and how they can help them cope.
NM4252GN **$14.95**

What on Earth Do You Do When Someone Dies
Trevor Romain
A down to earth explanation for children about death. It offers many ways for children to cope with and understand what is happening.
FS4000E **$7.95**

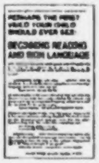
Guiding Your Child Through Grief
Mary Ann Enswiler, MA, MRS, and
James P. Enswiler, MA, M.Ed
This caring and compassionate guide offers expert advice during the difficult days to help a child grieve the death of a parent or sibling. This book helps readers understand the many secret ways children grieve and offers more insight information, and advice that can help a child heal.
BD0257GR **$13.95**

HEARING IMPAIRED



The Young Deaf Child
David M. Luterman, Ellen Kurtzer-White, and Richard C. Seewald
A fascinating review of the historic treatment of deaf children, and an outline of what has been proven to be best for the child, early intervention, maximization of technology, and strong family involvement. A must have for all who live with someone who is deaf.
YP2467DE **$28.00**

Sign Songs
Fun Songs to Sign and Sing
National Theatre of the Deaf
A video that is designed for both children and parents alike, offering a fun way to learn to sign and communicate with those who are hearing impaired. Video 29 minutes/Color
AY100HI **$19.98**



Beginning Reading and Sign Language
A video for those who wish to have their children learn sign. It is user friendly to both the hearing impaired and those who wish to learn sign as a form of communication with those who are hearing impaired.
AY300HI **$19.99**

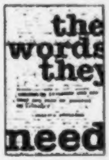
Kid-Friendly Parenting With Deaf And Hard Of Hearing Children
A Treasury of Fun Activities Toward Better Behavior
Daria Medwid and
Denise Chapman Weston
A step-by-step guide offering hundreds of ideas and methods designed to work with children ages 3 to 12 to enhance communication and strengthen relationships in skillful, fun ways.
GU101DF **$24.95**

Chris Gets Ear Tubes
Betty Pace Illustrated by
Kathryn Hutton
An explanation of what happens before, during, and after the surgery in language a child can understand. It takes away the child's natural fear of the unknown.
GU102YP **$9.95**

Learn to Sign the Fun Way
Penny Warner
Never before has learning to sign been so simple and so much fun. Whether you are a teacher or a parent, this lively self guided book of American Sign Language (ASL) will quickly become your kids' new favorite teacher. This text goes beyond the manual alphabet and teaches the beautiful language of sign in a simple, interactive format.
PR2633HI **$14.95**

HEARING IMPAIRED

My First Book of Sign
Pamela J. Baker, Illustrated by Patricia Bellen Gillen
A full color alphabet book, giving the sign for 150 words most frequently used by young people. Word choice based on early language acquisition. Appropriate for children beginning to read.
GU106DF $14.95



The Words They Need
Welcoming Children Who Are Deaf And Hard Of Hearing To Literacy
Jessica Stelling
An in depth examination of the relationship between acquisition of vocabulary, grammar and reading within the needs of the child who has hearing impairments.
YI001HI $29.50

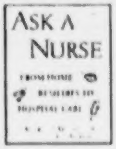
Sign and ABC's
A New Way To Play
National Theatre of the Deaf
A fun video that teaches adults and children how to sign the alphabet, and offers an introduction to spelling. Color/50 minutes
AY200HI Video $14.98

Moses Goes To A Concert
Isaac Millman
A story about a hearing impaired going to a concert for the first time and his experiences at this special event. The book is written in sign and english.
HH105HI $16.00

HEALTHCARE

Working with Your Doctor
Getting the Healthcare You Deserve
Nancy Keene
An education for even the most savvy consumer of healthcare. Covers every aspect of the field from choosing a doctor to getting what you need from your managed care provider.
OA102HC $15.95

Yoga For The Special Child
A Therapeutic Approach for Infants and Children
Sonia Sumar
An innovative and easy to follow program for parents, educators, yoga teachers, and healthcare professionals. This book includes a step by step integrated system of yoga poses designed to increase cognitive motor skills in children with learning and developmental disabilities.
SY240XHC $19.95

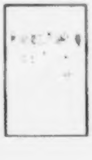


As A Nurse
From Home Remedies to Hospital Care
Edited by: Geraldine Bednash, Ph.D., R.N., FAAN
This book provides comprehensive information on standard treatments, home remedies, and effective over-the-counter medications for health problems ranging from allergies to yeast infections. With the expertise of 550 nursing schools and personal advice from 100 registered nurses nationwide, you can learn what to do whey your or a family member is sick and in need of care. Chapters are arranged alphabetically so it is easy to find what you need.
SS6875GN $30.00

Transcultural Aspects of Perinatal Health Care
A Resource Guide
National Perinatal Association
Offers resources and information supporting requirements of the Office of Civil Rights, the Maternal and Child Health Bureau of HRSA, and JCAHO in Cultural Sensitivity, Cultural Competency, Core Health Status Indicators, Developmental Health Status Indicators, Interpreter Competency and patient education. A great source for Title V Applications. User friendly binder chapters include narrative and support sections; accompanied with a CD-ROM to facilitate searching and referencing. Periodic updates will be available in choice of E-Mail, CD-ROM or printed copy.
EP8020PH $69.00

HOME SCHOOLING

The First Year of Homeschooling Your Child
Your Complete Guide to Getting Off to the Right Start
Linda Dobson
This comprehensive guide is designed to help you determine the appropriate first steps, build your own educational philosophy, and discover the best ways to cater to your child's specific learning style, including: When, why, and how to get started; The best ways to develop an effective curriculum, assess progress, and navigate local regulations; Kid tested and parent approved learning activities for all age levels and much more.
PR7885HS $16.95



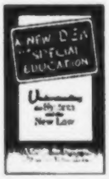
The Homeschooling Handbook
Mary Griffith
Homeschooling is an awesome responsibility and a tremendous opportunity. It isn't for everyone, but it may work for you and your child. This text will help you decide. Topics included are: When, why, and how; An overview of regulatory issues; Options- who stays home to teach, how to schedule around other responsibilities; Special assistance for learning disabilities and physical disabilities and much more.
PR1924HS $14.00

Homeschoolers' Success Stories
Linda Dobson
15 adults and 12 young people share the impact that homeschooling has made on their lives. This is not a how to book but rather a how it was done book.
PR2557HS $16.95

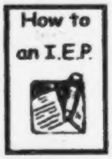
Homeschool Your Child For Free
Laura Maery Gold and Joan M. Zielinski
An invaluable guide to all the best in free educational material - from reading-readiness activities for preschoolers to science projects for teens-categorizes, reviews, and rates more that 1200 of the most useful educational resources on the Internet and beyond. Includes Legal guidelines and compliance requirements; complete curriculum plans for a comprehensive education, from preschool through high school; On line lesson plans arranged by subject and much more.
PR5130HS $18.95

IEP

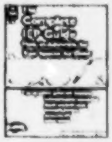
Planning For Success
The College Application Process for Students With Learning Disabilities
The college admission process can be a confusing and overwhelming experience for students with learning disabilities and their families. This comprehensive video enables you to see the college application process from the very beginning. It shows early planning, college visits, the essays, and how to choose the best school for you.
LD201LD $79.99



A New IDEA For Special Education: Understanding The System And The New Law A Guide for Parents, A Tool for Educators
Through examination of IDEA provides insight as to role of parent and rights of children. Topics include: the new law; the referral process; child evaluation; creation of IEP; placement and related services; transition preparation; and more.
EV173SE Video $49.95



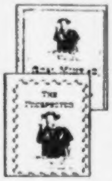
How To Write An I.E.P.
Third Edition
John Arena
The overall concept in preparing this revised edition was to provide teachers, parents, administrators and others involved in IEP preparation and implementation an easy to use guide. It is meant to be a reference for making sure that all factors of consequence are given the consideration they require.
AT1649SE $19.95



The Complete IEP Guide
How to Advocate for Your Special ED Child
Newly Revised
Lawrence M. Seigel

A comprehensive step by step guide through the entire IEP process that provides encouragement to the reader as it takes a complicated process and makes it easier to understand. Provides instructions, suggestions, strategies, resources, forms and much more.

NL001SE $24.95



The Prospector Goal Mine
Donald Cahill and Maureen Cahill

Written in parent-friendly language; designed to help parents and educators through the Individualized Educational Plan (IEP). Segmented into 26 educational needs areas. Includes more than 5000 examples of good goals and objectives and their application.

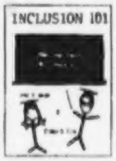
IE400ED $39.95

INCLUSION

Everybody Belongs
Changing Negative Attitudes Towards Classmates with Disabilities
Dr. Arthur Shapiro

A teacher's ability to recognize and counter negative images that can promote prejudice towards those with disabilities may well determine the success of inclusion and mainstreaming programs in our schools. Well written and well researched this book offers practical guidance to schools and teachers that are wrestling with mainstreaming children with disabilities.

TF9607SE $28.95



Inclusion 101
How to Teach All Learners
Anne M. Bauer, Ed. D. and Thomas M. Shea Ed.D.

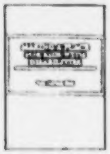
In each classroom there are students who vary significantly from their peers in terms of interactions and learning styles. According to the authors, this essentially makes every classroom an inclusive one, regardless of design. This book illustrates how teachers can assess classroom environments and situations, develop and implement effective inclusion strategies, promote active participation, and do much much more.

PB3726IN $35.00

Inclusion: An Essential Guide For The Paraprofessional
A Practical Reference Tool for All Paraprofessionals Working in Inclusionary Settings
Peggy A. Hammeken

Partnership is a key to inclusive education and the paraprofessional is an indispensible member of the team. This resource contains more than 300 easy-to-use strategies for use in the classroom and school environment. Many reproducible forms.

PP210ED $21.95



Making A Place for Kids with Disabilities
Dr. Dale Boreman Fink

The first book to examine the increasing participation of children with disabilities in large social groups such as the Boy Scouts. An excellent case study that helps to show exactly how and what true inclusion in society is.

GP8265GR-SOFT COVER $24.95

Inclusion
A Guide for Educators
Susan Stainback & William Stainback

A comprehensive guide for parents and educators providing practical strategies that capitalize on differences among students and school personnel to enhance social success and educational achievement for all students.

PB1360D $37.00

Teachers Ask About Sensory Integration
Audio Cassette and Companion Booklet
Stacey Szklut with CarolStock Kranowicz

A full length discussion of SI dysfunction as it relates to the teaching environment. The companion booklet contains a complete appendix, glossary, resource list, and a variety of performance checklists.

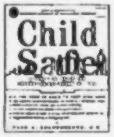
BC300SI $21.00

INJURY

Your Child In The Hospital
A Practical Guide for Parents
Nancy Keene & Rachel Prentice

This is a book of tips and wisdom from veteran parents that will help make any hospital stay easier. Includes essential information on preparation; packing; coping, preparation for surgery; feelings and behavior and much more.

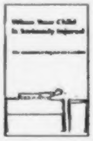
OA100IS $11.95



Child Safe
A Practical Guide for Preventing Childhood Injuries
Mark A. Brandenburg, MD

Everyone who has kids knows how easily children get hurt. A practical parenting book, Child Safe, will help keep kids out of trouble and will help parents recognize the dangers that are potentially harmful to kids and provide concrete ways of preventing specific injuries.

RH412XCH $14.00



When Your Child is Seriously Injured
M. Lash, M.S.W.

Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.

EP005ML $4.50

When Young Children are Injured
Families as caregivers in hospitals and at home
J. Haltiwanger, M.A., Ed M. & M. Lash, M.S.W.

A book about the family's role in caregiving when a young child is injured. Written for families with young children who have sustained debilitating injuries.

EP085ML $7.50

LEARNING DISABILITIES

Somethings Not Right
One Family's Struggle With Learning Disabilities
N. Lelewer

From the perspective of a mother with dyslexia, this compelling story tells how she ensured that all her children received a good education, despite three of her four kids had learning disabilities.

VB133LD $14.95

Many Ways to Learn
Young People's Guide to Learning Disabilities
Judith Stern, M.A., Uzi Ben-Ami, Ph.D.

This book is written for young people ages 8-14. Reading it will help them learn to help themselves as it provides a clear and positive understanding of what it means to have learning disabilities.

AP123LD $12.95

Learning Disabilities and ADHD A Family Guide to Living and Learning Together
Betty B. Osman, Ph.D.

Vital information on early signs and symptoms of learning disabilities and ADD/HD; latest advances in educational, medical and psychological treatments including drug and behavior therapies; how learning problems affect the whole family; and more.

JW122LD $14.95

I Wish I Could Fly Like A Bird
Audio Tape and Book
Katherine Denison

Children who have been taunted for being different, who have ever felt embarrassed socially, who have resorted to bravado in the face to shame will understand Chic I. Dee, a boy bird who discovers his talents; trusts his intuition; and finds his own way.

WCE001LD $17.95

The Experts Speak
Parenting the Child With Learning Disabilities
Teresa A. Citro

A clear, comprehensive, and direct collection of writings by professionals in the field of learning disabilities in their area of concentration. Whether it is teaching, parenting, or socialization there are stories on it here.

LD200LD (English) $18.99
LD7129LD (Spanish) $18.99

LEARNING DISABILITIES

Einstein and Me: Talking About Learning Disabilities
A Video for Parents, Kids & Teachers
Jerome J. Schultz, Ph.D.
An upbeat, informative and optimistic video of kids talking openly and honestly, telling about how they found out about their learning disability; policies and people who make life difficult; people and programs that helped them cope; their strengths and talents.

LD100LD $99.00

MENTAL RETARDATION

Retarded Isn't Stupid, Mom!
At 2 She was labeled Mentally Retarded, at 22 she was living on her own
Sandra Z. Kaufman
A fast paced engaging story where the mother of a two year old mentally retarded child reveals her feelings of denial, guilt, frustration, eventual acceptance, and the resulting determination to help her child live an independent life. Every accomplishment of the child brings hope, and every outcome teaches others about setting expectations.

PB3785MR $22.95

A GUIDE TO CONSENT
AAMR

A Guide To Consent
AAMR
An examination of current consent issues and exploration of the policy, legal and programmatic implications of topics vital to self-determination. Written by nationally known experts who focus on critical life events of people with mental retardation and practical application of consent.

ME100MR $49.95

The Burden of Sympathy
How Families Cope with Mental Illness
David A. Karp
This book captures the essence of caring and caregiving for society today. It carefully discusses the emotional and social forces that are at play when caring for a mentally ill person.

OU3158MR $25.00

Genetics and Mental Retardation Syndromes
A New Look at Behavior and Interventions
Elisabeth M. Dykens, Robert M. Hodapp, and Brenda M. Finucane
This comprehensive guide identifies the genetic and behavior characteristics of nine specific genetic mental retardation syndromes. It contains accessible in-depth information on causes, prevalence, physical and medical features, and cognitive profiles among other things.

PB4714MR $29.95

Speakeasy
Karin Melberg Schwier
People with mental handicaps talk about their lives in institutions and in the community.

PE044MR $16.00

Before and After Zachariah
A True Story About A Family and A Different Kind of Courage
Fern Kupfer
A gripping autobiographical tale of a parent's heart wrenching decision on how to care for their newborn brain damaged son. Here we learn there are alternatives and that they, too, are honorable.

AP111GN $14.00

MENTAL RETARDATION — 21st CENTURY

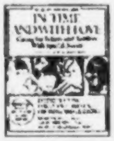
Mental Retardation in the 21st Century
Sponsored by The ARC of the United States, Edited by: Michael L. Wehmeyer and James R. Patton
An interesting and provocative prediction of where technology and society are headed with respect to the treatment of mental retardation in the coming century. Seven Sections covering Family Issues; Education Issues; Employment and Residential Issues; Psychology Issues; Medicine and Health Issues; Life Span Issues and Policy Issues.

PE181MR $ 44.00

PARENTING

Special Children Challenged Parents
Robert A. Naseef, Ph.D.
The Struggles and Rewards of Raising a Child with a Disability
When a child is born, family life changes forever. If that child has special needs, the changes can seem overwhelming. What are the daily blessings and challenges that await parents when their child is not who they expected? How can they deal with their complex emotions, build a relationship with their special child, and maintain family unity? Dr. Naseef, a professional psychologist and father of a son with autism, answers these critical questions with keen insight and honesty.

PB5354GN $21.95



In Time and With Love
Caring for Infants and Toddlers With Special Needs
Marilyn Segal, Ph.D.; Wendy Masi, Ph.D., Roni Leiderman, Ph.D.
This new completely revised and updated Second Edition is written in jargon free, parent friendly style and illustrated with 100 photographs. Filled with advice on feeding, dressing, disciplining, teaching, and assisting special needs children and includes topics such as games and activities to promote social and emotional development, encourage motor and language skills and much more.

NM4457GN $18.95

PHYSICALLY DISABLED

Special Offer ONLY $99.00

The Challenge of Osteoporosis For People With Disabilities
A look at risk factors and prevention
Ian Smith, M.D.
May of the 54 million Americans with disabilities including those with cerebral palsy, muscular dystrophy, multiple sclerosis, spina bifida and other physical disabilities face special health challenges. Osteoporosis, or thinning and weakening of the bones, is one of the most critical. This 15 minute, full color, broadcast quality video comprehensively explores the impact of osteoporosis for individuals with physical disabilities. Developed as an informational and training tool for a wide audience, including people with disabilities and their caregivers as well as the general public.

UCP010S $149.00

Torticollis
Differential Diagnosis, Assessment and Treatment, Surgical Management and Bracing
Karen Karmel-Ross, PT, PCS, LMT
Clearly reflects the philosophy of the team approach by including contributions from a pediatric orthopedist, pediatric general surgeons and several pediatric physical therapists. Reviews the differential diagnosis and surgical management of CMT and provides a detailed, comprehensive approach to the nonoperative management of CMT by bringing together a wide range of related materials under one cover.

HP3171OS $24.95

EASY FOR YOU TO SAY

Easy for You to Say
Miriam Kaufman, MD
Q & As for Teens Living With Chronic Illness or Disability
This book addresses issues faced by teens and young adults with disabilities and chronic conditions. The information is presented in a straightforward questions and answer format that can easily be browsed through, rather than read cover to cover. Divided into eight chapters to enable the reader to jump to a topic of interest such as Doctors and Medical Issues; Friends and Dating or Sexuality plus much more.

KP6194CI $15.95

No One's Perfect
Hirotada Ototake, translated by Gerry Harcourt
This is the remarkable autobiography of a Japanese man who was born without arms or legs. A true account of how he slam dunked one challenge after another, including basketball. This young man proves time and again that hard work, humor, versatility, and an upbeat approach to life are as valuable as limbs.

OU5009PD $19.95

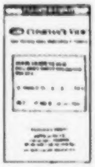
Nick Joins In
Joe Lasker
A free, appropriate public education is guaranteed for all handicapped children and whenever possible, they will be educated alongside non-handicapped children, a practice known as "mainstreaming". This book may help overcome child's apprehension.
AW1180D $14.95

Raising A Child Who Has A Physical Disability
D.G. Albrecht
This book will make your job easier. Compassionate, helpful, and based on real-life experience, it will help you handle every facet of raising and loving your special child.
JW1210D $12.95

POTTY LEARNING

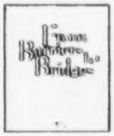
The Potty Chronicles
A Story to Help Children Adjust to Toilet Training
Written and Illustrated by Annie Reiner, L.C.S.W.
The book expresses children's common fears and therefore enables them to gain comfort and trust in the knowledge that their parents understand what they are experiencing. This understanding will help a child through this difficult stage.
AP121YP $8.95

Once Upon A Potty
Alona Frankel
Learning to use the potty is often a lengthy process, taxing the patience of both parent and child. When success finally comes—and it should come in its own good time without undue pressure or haste—it enhances the child's confidence and pride. This illustrated story for children is best used as a companion volume to a child's new potty to provide encouragement.
NC321YP (For Boys) $5.95
NC322YP (For Girls) $5.95



Potty Learning For Children Who Experience Delays
S.R. Hays, M.S. R.N., C.R.R.N.
This video presents a unique developmental approach to supporting the child in learning independence in the management of "bathroom" skills.
ED0770D $39.95

RELIGION

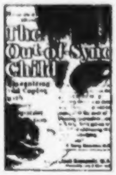


From Barriers to Bridges
A Community Action guide for Congregations and People with Disabilities
Edited by G. Thornburgh
Designed to foster dialogue Between people with disabilities, their family members, religious leadership and the larger community.
ND1570D $10.00

Loving Justice
The ADA and the Religious Community
Edited by G. Thornburgh
How the Americans with Disabilities Act affects religious institutions, including congregations, hospitals, nursing homes, seminaries, universities and more.
ND1000D $10.00

That All May Worship
An Interfaith Welcome to People With Disabilities
G. Thornburgh
An interfaith handbook to assist congregations in welcoming people with disabilities to promote acceptance and full participation.
ND0840D $10.00

SENSORY INTEGRATION



The Out-of-Sync Child
Recognizing and Coping with Sensory Integration Dysfunction
Carol Stock Kranowitz, M.A.
Comprehensive yet easy to understand language about a disability that is often misdiagnosed as ADD/ADHD. Includes examples of typical indicators with check list to determine existence of condition; helpful tools for parents to promote healthy integration.
GP174LD $14.00

Songames for Sensory Integration
Aubrey Lande, MS, OTR, Bob Wiz and Friends
A therapist's wish come true!! This 87 minute audio tape contains 25 games that offer long-lasting fun and engaging developmental play activities for any kid age 3-8. The games are created by therapists for improving fine and gross motor skills, muscle strength and praxis. Enhances oral motor skills and expressive language play while promoting growth in a fun, safe, and positive environment. Includes 80 page booklet.
BC5625SI $ 24.99

Making Sense of Sensory Integration
Jane Koomar, Ph.D. Stacey Szlut, M.S. & Sharon Cermak, Ed.D.
A discussion by respected and knowledgeable occupational therapists to help parents and educators learn more about sensory integration (SI); what it is, how it will affect the child, the family at home, and at school. Includes resource book.
BC100SI $29.95

SIBLINGS

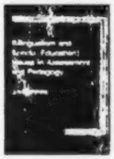
Mom He Hit Me!
What To Do About Sibling Rivalry
Elaine K. McEwan
Sibling rivalry begins when the new baby comes home from the hospital and may not end until the siblings all move away. This practical book includes tips that will help parents minimize the natural rivalries between children.
WP5567GN $6.99

Views from our Shoes
Growing up with a brother or sister with special needs
Donald Meyer
A new book for children by children who share their experience as the brother or sister of someone with special needs—The good and bad aspects, as well as many thoughtful observations. May be useful to educators to supplement their inclusion programs.
WB1720D $14.95

It Isn't Fair!
Siblings of Children with Disabilities
Edited by S.D. Klein & M.J. Schleifer
Features chapters by parents, siblings and professionals.
EP001EP $19.95
By Exceptional Parent's Co-Founder

Sisters, Brothers, and Disability *A Family Album*
Lydia Gans
The stories of 26 families raising children with special needs at home. Includes 142 photographs that show compassion, patience, and matter-of-factness sisters and brothers share as they deal with the challenges of living with differently-abled sibling.
FP0100D $14.95

SPECIAL EDUCATION



Bilingualism in Special Education
Issues In Assessment And Pedagogy
Jim Cummins
This valuable data-based work should be read by everyone involved in special education. It raises a number of important and timely questions about diagnostic methods and tests as well as appropriate classroom structure and curricula.
PE130SE $33.00

All My Life's A Circle
Using the Tools: Circles, MAPS & PATHS
Mary A. Falvey, Marsha Forest, Jack Pearpoint, Richard L. Rosenberg
This new and expanded version explores the teaching and learning tools os MAPS and PATHs. These techniques enable individuals to learn at their own speed with encouragement and pushes from educators and parents. It also gives children a perspective of their circle of friends and supporters, ranging from family to teachers.
IP8267IN $15.95

The History of Special Education
From Isolation to Integration
Margaret Winzer
A look at how special education came about, and the struggles that those with special needs faced when trying to get an education without it.
GU111ED $55.95

SPECIAL EDUCATION

Free Appropriate Public Education
The Law and Children with Disabilities: Sixth Edition
H. Rutherford Turnbull and Ann Turnbull

This completely updated text contains all the 1999 rules and regulations made to the 1997 reauthorization of IDEA. Also includes the pre-1997 provisions of IDEA so that comparisons to the current law can be made. Cases presented represent those that are widely regarded as "leading" and recent and represent an established body of law. Focuses on most important special education law cases and gives detailed analysis of the courts' decisions. Includes glossary to explain legal terminology.

LV140ED **$70.00**

SPINA BIFIDA

An Introduction to Spina Bifida
David G. McLone, M.D., Ph.D.
and Joy Ito, R.N.

The purpose of this book is to aid the parents, family and non-medical people who care for the child born with spina bifida. Revised 1998

SB095SB **$6.00**

Medical Facts About Spina Bifida
C.T. Davoli, M.D. & S.L. Kinsman, M.D.

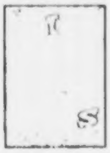
Information to answer your basic questions about spina bifida.

KK151SB **$4.00**

Children With Spina Bifida
A Parent's Guide
Marlene Lutkenhoff, R.N., M.S.N.

A compassionate easy to understand volume that provides parents with information, guidance, and support to help meet their child's needs from birth through childhood.

WB201SB **$16.95**



Spinabilities
Edited by Marlene Lutkenhoff, R.N., M.S.N.,
& Sonia G. Oppenheimer, M.D.

Young people with spina bifida will learn answers to questions about managing life, positive attitude development, and goal setting to become independent. Parents will get overview about adolescent children with spina bifida.

WB170SB **$16.95**

Available in Spanish

Answering Your Questions About Spina Bifida
A Guide from the Spina Bifida Program Department of General Pediatrics
Edited by C. Shaer

Contains information to help understand basic medical, educational, and social issues of children and adults with spina bifida.

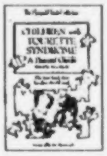
CN152SB-english **$6.95**
CN153SB-spanish **$6.95**

TOURETTE SYNDROME

Tourette's Syndrome
Finding Answers & Getting Help
Mitzie Waltz

Tourette's syndrome is a neurological disorder usually diagnosed in childhood. Tics; physical jerks and involuntary vocalizations characterize it. Some people with Tourette's also have other brain-based disorders, particularly ADHD or OCD. This book is designed to help you: Secure an accurate and complete diagnosis; Live with Tourette's in the family; Understand medical interventions; Obtain appropriate medical care from an existing health plan; Find resources and much more.

OA0076TS **$24.95**



Children with Tourette Syndrome
A Parents Guide
Edited by T. Haerle

Written by a team of professionals and parents, this book covers medical, educational, legal, family life, daily care, and emotional issues.

WB0160D **$14.95**

VISUAL IMPAIRMENT

Transition Issues Related to Students with Visual Disabilities
Jane N. Erin and Karen E. Wolffe

An explanation and analysis of the critical areas in the lives of those with visual impairments, such as transportation, academics, employment and recreation.

PE168VI **$9.95**

Children with Visual Impairments
A Parents' Guide
Edited: M. Cay Holbrook, Ph.D.

Designed to help parents get a handle on common types of concerns. Written by a team of professionals and parents, each of whom is an expert on a different aspect of caring for children with visual impairments.

WB1790D **$16.95**

YOUNG PEOPLE

Eddie Enough!
Debbie Zimmett, Illustrated by: Charlotte Murray Fremaux

This book features a third grade boy with attention deficit/hyperactivity disorder. Eddie talks non stop, takes the stairs two at a time, and has the annoying habit of bumping into people. Then one day Eddie's life goes from bad to worse. A sequence of event lands him in the principal's office and earns him the new nickname of "Eddie Enough." An understanding principal and therapist help put the pieces together so Eddie learns to control his behavior and begins to feel better about himself and in the end feels like "Eddie Just Right!"

WB7259YP **$14.95**

Russ and the Apple Tree
Janet Elizabeth Rickert with photography by Pete McGahan

A story about an energetic young boy with Down Syndrome who finds out how much fun an apple tree in his back yard can be.

WB202YP **$14.95**

Waiting for Mr. Goose
Laurie Lears with illustration by Karen Ritz

An inspiring story about a young boy with ADHD who creates an innovative plan to help a goose who has been caught by a hunting trap.

AW131YP **$14.95**

Little Tree
A Story For Children With Serious Medical Problems
Joyce C. Mills, Ph.D.

Written for children ages 4 to 8 who experience life-challenging illness or accidents and who often feel overwhelmed and helpless. This story may help them find comfort, inspiration, and an inner sense of well-being.

AP127CN **$8.95**

We Can Do It!
Laura Dwight

Five small children, each with a disability, tell all that they are able to do. Each has a restrictive condition but manages to have a full and rewarding childhood.

CH094GN **$13.95**

(ALSO AVAILABLE IN SPANISH AT SAME PRICE)

Susan Laughs
Jeanne Willis and Tony Ross

Susan laughs, she sings, she rides, she swings, she gets angry, she gets sad, she is good, and she is also bad. In fact, despite her physical challenges, Susan is no different from any other child. With Insight and subtlety, and without sentimentality, this story illustrates a happy little girl whose physical challenges are never seen as handicaps.

HH110YP **$15.00**

Sugar Was My Best Food
Diabetes and Me
Carol Antoinette Peacock, Adair Gregory, Klye Carney Gregory

Nine year old Adair tells of how diabetes brought big changes to his life. Little by little, he and his family learned to manage his illness, and after awhile life got better. This true story will help other kids in their struggle with diabetes. Ages 8-13.

AW123DI **$13.95**

Always Accept Me for Who I Am
Instructions from Teenagers on Raising the Perfeci Parent
Compiled by J. S. Salt

Instructions on raising the perfect parent as seen through the eyes of 147 teens who know.

HH116YP **$8.00**

Julie's Beach Adventure

Created and Written by Anne Manuel Illustrated by William Langley Studios, Inc.

First issue in the Friendship Circle series of stories where differences don't matter and warm hugs, understanding, sharing, caring and giving are part of everyday. In the Friendship Circle every member is special and appreciated.

WP010CP **$5.95**

Searching the Noonday Trail

The Gun Lake Adventure Series

Johnnie Tuttel and Sharon Lamson

The first day at a new school proves to be challenging. But will it be as adventuresome as the summer was? Johnnie Jacobson is not too sure. But a secret football play and a field trip to where Chief Noonday and the Ottawa tribe used to live put Johnnie and his Gun Lake friends hot on the trail of another exciting adventure.

TS7533YP **$6.99**

Proud of Our Feelings

Lindsay Leghorn, M.Ed., M.S.W.

Provides children with an entertaining and constructive way to learn to accept and appropriately express their emotions. Helps stimulate discussion and interaction between children and adults so they can explore and openly discuss their unspoken feelings helping to build self-trust and emotionally well-balanced people.

APL35SE **$14.95**

What About Me?

When Brothers and Sisters Get Sick

Allan Peterkin, MD

About 1 in 12 children and adolescents are living with chronic illness or disability. Most have brothers and sisters. With the intense focus on the sick child, the feelings and needs of the siblings can easily go unnoticed by overwhelmed parents. This book helps to address that issue in a meaningful way.

APL37OD **$8.95**

A Gran-Gran's Best Trick

A story for Children who Have Lost Someone They Love

L. Dwight Holden, M.D. Illustrated by Michael Chesworth

Written to help children deal with the loss of someone they love, and to help parents help their children with that loss. It is also about how we grow from that experience and how those we love never leave our hearts. That is love's best trick.

APL26GN **$8.95**

My Brother, Matthew

Mary Thompson

When a child with disabilities is born into a family, life typically shifts to focus on this child's special needs. Siblings often have difficulty adjusting and feel left out. This realistic and compassionate tale tells what happens and what it is like.

WBLX10D **$14.95**

How Many Days Until Tomorrow?

Caroline Janover

Josh, a 12-year old with dyslexia, is spending the summer with his older brother and grandparents on a remote Maine island. This is the story of how he finds adventure and discovers new talents in the sometimes rugged wilderness of Maine.

WB7224FY **$11.95**

The Canaloupe Cat

Jan Yager with illustrations by Mitzi Lyman

A tale about a cat who does not act like other cats. When they chase string he sits in the kitchen eating cantaloupe. This unique and fun story illustrates the importance and acceptability of uniqueness and it also approaches the idea of reexamining stereotypes.

HAZ129YP **$15.95**

Andy and his Yellow Frisbee

Written and Illustrated by Mary Thompson

Introduces young readers of elementary school age to autism. Illustrated with vivid watercolors and designed to be shared with friends, siblings and classmates so they may get a better understanding of a disability that they have had little exposure.

WB1750D **$14.95**

A Button in Her Ear

Ada B. Litchfield

Pictures: Eleanor Mill

Approximately 7% of school children have some degree of hearing loss. Story reinforces a child's healthy attitude toward use of a hearing aid. For children in similar circumstances this story has special meaning and sets the stage for new understanding.

AW116DF **$14.95**

Sammy the Elephant & Mr. Camel

A Story to Help Children Overcome Bedwetting While Discovering Self Appreciation

Joyce C. Mills, Ph.D.
& Richard J. Crowley, Ph.D..
Illustrated by Germaine Cook

A delightful and profound story that can be enjoyed by children of all ages. The theme is of a struggling youngster who is guided to discover his own unique abilities will touch the heart of any child in a universal way. Words are in italics for emphasis.

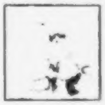
APL28GN **$8.95**

Let's Talk About It: Extraordinary Friends

Fred Rogers

This book lays the foundation for helpful talk and careful listening in any family. If children can learn to talk about their feelings when they are young, they can take that gift with them throughout their lives. Fred Rogers, of Mister Roger's Neighborhood, authors this exceptional text for children and parents.

GP1463YP **$16.99**



What's Wrong With Timmy

Maria Shriver, Illustrated by Sandra Speidel

All children ask questions that are difficult to answer. What then is the best response when a child points out that a disabled child or adult looks and acts "different"? In this book, remarkable for its sensitivity and generosity of spirit, Maria Shriver uses her story telling art to provide some answers. With a special insight that derives from her and her family's involvement with the rights of the disabled, the author deepens our understanding as she introduces us to a terrific kid named Timmy, someone who wants what we all want—to be included and loved.

TW3374YP **$14.95**

Ask about our bulk order discounts for starting or refreshing your resource library

Exceptional Parent Library Order Form

Mail to: **Exceptional Parent,** Dept. EP0201, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, **Or call 800•535•1910**

QTY.	ITEM#	UNIT PRICE	TOTAL
		Sub-Total	
		NJ Residents 6% Sales Tax	
		Shipping	
		TOTAL	

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

These prices are subject to change without notice.

Name ____

Address _______________________________________

City___________________________ State _______ Zip __________

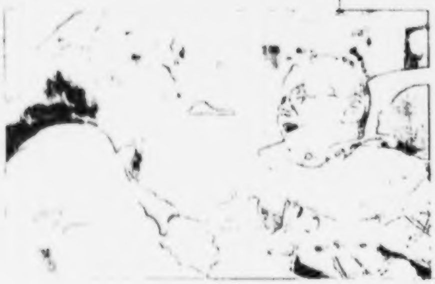
Telephone ____________________ E-Mail _______________________

I have enclosed my check payable to Exceptional Parent or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover

Account Number: ____-____-____-____ Exp. Date ____/____

Signature ____

Circle #300



Changing
Lives
Forever

The Anne Carlsen Center for Children offers a 60-year tradition of residential, therapeutic and educational services on one campus. Our individualized services include care for children and young adults coping with cerebral palsy; orthopedic, vision and hearing impairments; autism, pervasive and other developmental disorders; and many other medical challenges. Our multidisciplinary team can reach out to you by conducting evaluations in your child's home and school setting.

**Anne Carlsen
Center for Children**
Changing lives forever

Jamestown, North Dakota
Call 1-800-568-5175 or visit our
web site at: annecenter.org

Circle #23 or visit www.eparent.com/adinfo

Shop
On-line!

Adaptivemall.com™

Tim's daughter Carrie... a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.
Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #27 or visit www.eparent.com/adinfo

Guldmann
Ceiling lifts

Easy to use ceiling mounted transfer systems for physically challenged individuals.

- **Battery operated**
- **Used for lifting from wheelchair to bed, floor or bathroom facilities**
- **Used independently or with assistance**
- **Mobile floor models also available**

Call today for a free evaluation of your transferring requirements and for the ceiling lift representative nearest you.

Guldmann, Inc. 1-800-664-8834
813-880-0619
813-880-9558 FAX

Circle #66 or visit www.eparent.com/adinfo

PEACE OF MIND

When it comes to your child, you don't compromise.
Safety is indispensable. You demand quality.
Reliability. Functionality.

The Lisa pediatric postural mobility system from Otto Bock gives you all this while maintaining its playful good looks. So go ahead. Take it "off sidewalk". Recline the back rest up to 130°. Accessorize to your heart's content. And enjoy how easily it folds and how little it weighs. You and your family deserve it.

For more information, visit
www.ottobockus.com,
or call 1-800-328-4058
to find a dealer
near you.

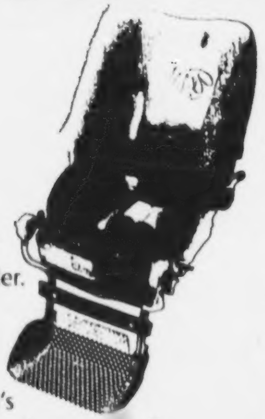
Otto Bock
HEALTH CARE
www.ottobockus.com

Circle #101 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

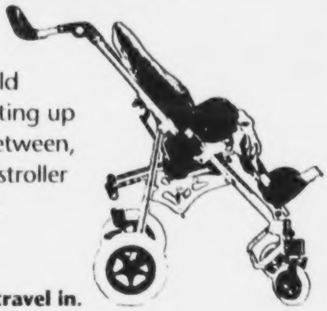
Well Adjusted.

Well Traveled.



Introducing the LEX EASyS rehabilitation stroller. Ergonomic. Adjustable. With its innovative and patented BSS® Balance Safety System, your child's hips and knees maintain a therapeutically correct angle even during recline. The stylishly designed seats are fully adjustable and come in two sizes—between the ages of 6 months to 5 years and 5 to 12 years old. So whether your child is laying down or sitting up or any position in between, there's a LEX EASyS stroller that will adjust to fit them perfectly.

EASyS Strollers.
A better position to travel in.



Thomashilfen
EASyS BSS
Distributed by

BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #33 or visit www.eparent.com/adinfo

Anchors in different locations when needed.

SUREHANDS®

Gary L., *accountant*, Warwick, NY - Becker's MD

At last, a Lift & Care℠ system as versatile as a pair of hands...and portable, too.

It's a motorized transfer device,
a positioning tool *for posture seating*,
a bathing support,
a hygiene helper *for toileting or diapering*,
a floor space-saver,
a standing support *for some*,
a dressing assistant,
and a back-saver *for carers*.

SUREHANDS LIFT & CARE SYSTEMS
Portable and permanent solutions for homes and workplaces.
1-800-724-5305
e-mail: info@surehands.com • website: www.surehands.com

Circle #123 or visit www.eparent.com/adinfo

Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS
Huggies
Pull-Ups
Disposable Training Pants
NEW!
HUGGIES
Supreme

Call for your free incontinence products catalog and receive a FREE $25 gift* with your first order.

DMP DURALINE®
1-800-654-3376
www.dmponline.com

Offer expires December 31, 2002. Available only to new customers, with a cash or credit card purchase over $35. Not valid with other offers. $25 gift is not pictured above.

10561

Circle #53 or visit www.eparent.com/adinfo

Life Sciences

Drug Discovery | Research | **Clinical Screening**

The first steps are
the Most Important for
Your Child

PerkinElmer Life Sciences is the world leader in providing tools for newborn screening. We are extending our commitment in this area by providing technology that enables testing for an expanded range of genetic disorders and inborn errors of metabolism. Tandem Mass Spectrometry technology is being used in an increasing number of states, providing early detection of more disorders, and enabling more timely treatment for affected children.

PerkinElmer
life sciences.

In the U.S.A.: PerkinElmer Life Sciences, 3985 Eastern Road, Norton, Ohio 44203-6215. Phone: 330-825-4525. Fax: 330-825-8520
In Europe: PerkinElmer Life Sciences, P.O. Box 10, Turku, Finland. Phone: +358 2 2678 111. Fax: +358 2 2678 332

www.perkinelmer.com/lifesciences

Circle #105 or visit www.eparent.com/adinfo

Universal Newborn Screening

In 1961, Dr. Robert Guthrie of the University of Buffalo developed a laboratory test to detect phenylketonuria (PKU) in newborns. PKU is an inherited metabolic disorder resulting from an enzyme deficiency; if left untreated, it results in profound mental retardation. In 1963 Massachusetts became the first state to mandate screening for PKU, which can be treated by lifelong dietary management and counseling. The National Association for Retarded Children (now The ARC), the Children's Bureau and the Kennedy Foundation were foremost among the organizations that pushed for widespread adoption of the Guthrie test, and by 1966 it was required for all children by all 50 states and the District of Columbia.

Dr. Guthrie and other researchers continued to develop newborn screening (NBS) tests to detect many more disorders, and each state decided what screens would be available for its newborns. Significant disparities resulted; in 1997, in Massachusetts, infants were tested for 10 or more disorders, while Utah's babies were screened for three. Montana and South Dakota each mandated three tests and offered one other by special request only. In the same period, with the introduction of ever-smaller and more powerful microprocessors, technology and equipment became significantly more sophisticated. This permitted testing that had not been feasible before. A process called tandem mass spectrometry (tandem MS, MS/MS) can now run tests for nearly 40 disorders at one time. None are curable, but all are treatable.

In the last two years, many states have expanded their NBS programs. Almost all Pennsylvania hospitals now offer the full spectrum of testing, although the law mandates testing for only six. Massachusetts routinely screens for more than 15 disorders and is running a pilot program offering 30+ tests. Wisconsin has almost tripled availability, from 7 tests to 20. Yet universal NBS still engenders much controversy, and there are many issues to be resolved before consensus can be reached on how the US will move forward.

The data tells us that of the four million babies born in the US each year, ten to twelve thousand may have one or more of these detectable...and treatable...disorders

ISSUES: These may be economic, political, professional, sociocultural, religious. Capital spending, training, payment policies, long-term follow-up; insufficient hard financial data; union issues; professional knowledge levels and practice habits; citizen knowledge, and cultural and religious beliefs and practices; insurance, managed care companies, Medicaid, ChIP programs, the uninsured–all these and many more must be part of discussions and resolution.

With the current system, a child born in Louisiana with galactosemia will likely live a life marked by mental retardation and other special health care needs, while similarly affected children born the same day in most of the rest of the country will receive immediate treatment and become productive members of society. The data tell us that of the four million babies born in the US each year, ten to twelve thousand will have one or more of these detectable disorders, an almost-negligible number. The overall cost or benefit to our society, though, will vary wildly from one child to another because of the patchwork of screening availability. We as a nation must find a way to embrace universal NBS and make it routine for all children born in the US. More than that, it is downright wrong not to do so when it has proven its worth time and again!

It is a question of education and awareness. Research shows that the average couple planning to have children does not know anything about existing screening programs, much less the capabilities offered by tandem MS, largely because OB/GYNs, pediatricians, genetic counselors and related professionals are not familiar with universal NBS. The education gap relates to professionals and consumers, rich and poor, people of every race, religion and ethnicity. Few people know much about any of the issues. Worse, among the people who do profess knowledge of NBS and the issues, a good deal of what they "know" is wrong.

The information you need on Newborn Screening is finally available on DVD and video

CHILDREN AT RISK
The State of Newborn Screening
Call for Special Introductory Price
DVD
VHS

Children at Risk:

The State of Newborn Screening

is now available on DVD and VHS. Introducing the first in a series of special educational programs presented by EP and the EP Foundation for Education, Inc., a 501(C)3 Not For Profit Corporation.

EP Foundation for Education, Inc. **Child Neurology Society** EP

Newborn screening can detect up to 39 metabolic disorders from one blood spot. All are treatable when diagnosed at birth, offering the chance for a full and productive life.

Leading medical and scientific professionals are gathered to provide the most current information available. You can view this valuable resource at your convenience and the DVD is indexed so that key topics are easily accessible.

Darryl DeVivo, MD
SIDNEY CARTER PROFESSOR OF NEUROLOGY
COLUMBIA UNIVERSITY

Piero Rinaldo, Ph.D.
DIRECTOR, BIOCHEMICAL GENETICS LABORATORY
THE MAYO CLINIC

Edwin Naylor, Ph.D.
PRESIDENT
NEOGEN SCREENING, INC.

Joan E. Pellegrino, MD
ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES
UMDNJ, ROBERT WOOD JOHNSON MEDICAL SCHOOL

Paul M. Fernhoff, MD
MEDICAL DIRECTOR
EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #74 or visit www.eparent.com/adinfo

FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

State Organizations, Chapters & Representatives Contact List

Throughout America, there is awakened awareness of the struggles, challenges, and untapped possibilities for children and adolescents with mental health needs. Effective family-driven advocacy ensures that children's mental health remains a highly visible, national priority. The Federation of Families for Children's Mental Health serves, with humility and determination, to provide and sustain leadership for a broad and deep nationwide network of family-run organizations.

We harness the passion (and we honor the cultural diversity) of our national membership and help focus it as a potent force for change in behalf of children with mental health needs and their families. We are passionate advocates at the national level for the rights of these children and families. We are equally passionate in transferring our insights and experiences to statewide family organizations, local chapters, and other family-run organizations so that skillful and effective advocacy can occur at state and local levels as well. We extend a lifeline to this network so that our partner organizations might draw strength from us and, in turn, better respond to the needs of families requiring guidance, training, support, and personal advocacy. Through our evolving relationships with these organizations, we jointly discover and share new models, new technologies, new tools, and new visions that enrich the capacities of our partners, strengthen our network, and allow us to serve with pride in this leadership role.

HOW TO USE THIS DIRECTORY

This directory includes the addresses and phone numbers of these projects. When available, e-mail addresses are indicated by the symbol ✉. Web sites are listed with the the standard **http://** before each. (Unless otherwise indicated, all telephone numbers are for voice only.) ✆ = Call before faxing. State Organizations (denoted by the symbol ◆) are statewide family-run organizations focused solely on the needs of children with mental health issues and their families. CHAPTERS (denoted by the symbol ○) are local family-run organizations with a similar focus.

Federation of Families for Children's Mental Health,
1101 King Street, Suite 420, Alexandria, Virginia 22314
(703) 684-7710, Fax: (703) 836-1040,
Web site: http://www.ffcmh.org ✉ ffcmh@ffcmh.org

This directory is provided by Federation of Families for Children's Mental Health.

CANADA, ONTARIO ○

Greater Toronto Area Chapter of the FFCMH
Lisa Ford
590 Davenport Road
Toronto, Ontario
Canada M5R 1K9
(416) 961-7392
Fax: (416) 935-0898 ✆

ALABAMA, BIRMINGHAM ○

Helping Other Parents Explore H.O.P.E. Alternatives
Jacquelyn P. Scales
940 Montclair Road, Ste. 200
Birmingham, AL 35213
(205) 595-4555
Fax: (205) 595-7499
✉lmoses@jbsmha.com

ALASKA, ANCHORAGE ○

Alaska FFCMH
Janet McGillivary
4045 Lake Otis Parkway
Ste. 209
Anchorage, AK 99508-5221
(907) 562-3649 (home)
(907) 563-0880
Fax: (907) 563-0881
(800) 478-0880
✉mhaa@alaska.net
http://www.alaska.net/~mhaa

ALASKA, WASILLA ○

Alaska Attachment & Bonding Association
Bernadine Janzen
3300 Palmdale
Wasilla, AK 99654
(907) 376-0366
Fax: (907) 376-3840
✉bsj@rogershsa.com
http://www.akattachment.org

ARIZONA, PHOENIX ◆

Mentally Ill Kids in Distress (MIKID)
Steven R. Isham & Nick DeHerrera
755 East Willetta, Ste. 128
Phoenix, AZ 85006
(602) 253-1240
Fax: (602) 253-1250
In-State: (800) 35-MIKID
✉MIKIDAZ@worldnet.att.net

ARKANSAS, LITTLE ROCK ◆

Arkansas FFCMH
Jane Burgan
Freeway Medical Center
5800 West 10th Street, Ste 101
Little Rock, AR 72204
(501) 537-9060
Fax: (501) 537-9062
Toll Free: (888) 682-7414

CALIFORNIA , BELLFLOWER ○

Bridging the Gap
Deah K. Lejon
9654 Prichard Street
Bellflower, CA 90706-3031

CALIFORNIA, NAPA ○

Matrix Parent Network
Joan Lockhart
2261 Elm Street
Napa, CA 94559
(707) 259-8174 or
(707) 253-8729
Fax: (707) 259-8651
✉jjklmatrix@aol.com

CALIFORNIA, SACRAMENTO ○

United Advocates for Children of California
Jennifer Clancy
DMH Specialized Programs,
UACC Project Office
1600 – 9th Street, Room 100
Sacramento, CA 95814
(916) 654-1364
Fax: (916) 654-1732
✉uacc@pacbell.net

CALIFORNIA, SAN DIEGO ○

Heartbeat Families Partnership
Celeste Hunter
Project Heartbeat
1357 Seventh Avenue, Ste. C
San Diego, CA 92101
(619) 615-7671 x25
Fax: (619) 615-6284
✉chnter@aol.com
http://www.sdhfp.org

CALIFORNIA, SAN FRANCISCO

Parents Helping Parents
594 Monterey Boulevard
San Francisco, CA 94127
(415) 341-8820
Fax: (415) 841-8824

COLORADO, DENVER ○

Colorado FFCMH
Susan Simic & Margie Grimsley
901 W. 14th Avenue, Ste. 1
Denver, CO 80204
(303) 572-0302
Fax: (303) 572-0304
In-State: (888) 569-7500

COLORADO, DENVER ○

Denver FFCMH / Aurora Chapter
Carmen Held
12485 E. 13th Avenue
Denver, CO 80011
(303) 343-1019
Fax: (720) 859-9367
✉carheld@msn.com

COLORADO, FORT COLLINS ○

Northern Colorado FFCMH
Marty Dwyer
1400 White Peak Court
Fort Collins, CO 80525
(970) 223-3036 (home)
Fax: (970) 377-0245 ✆
✉thefeds2@home.com

COLORADO, GRAND JUNCTION ○

Western Slope FFCMH
Janice Curtis
2840 Forest Court
Grand Junction, CO 81501
(970) 257-0891
✉jcurtis@frontier.net

CONNECTICUT, NIANTIC ○

Families United for CMH
Morgan Meltz
115 Roxbury Road
Niantic, CT 06357
(860) 439-0710
Fax: (860) 715-7098
✉ctfederation@aol.com
http://ctfamiliesunited.homestead.com

CONNECTICUT, WEATHERSFIELD

Village for Families & Children
Cindy Fenton
1680 Albany Avenue
Hartford, CT 06105
(860) 297-0598 x609
Fax: (860) 529-6833 x15 ✆
In-State: (800) 842-1501
✉cfenton@villageforchildren.org

DELAWARE, WILMINGTON

Mental Health Association of Delaware
Diane Treacy
812D Philadelphia Pike
Wilmington, DE 19809
(302) 765-9740
Fax: (302) 765-97456
✉dtreacy@mhainde.org

DISTRICT OF COLUMBIA ○

Family Advocacy & Support Association
Phyllis Proctor-Morgan
3700 10th Street, NW
Washington, DC 20010
(202) 576-5151
(202) 234-4387 (home)
Fax: (202) 576-8804
Home Fax: (202) 265-7877

FLORIDA, CRAWFORDVILLE ○

Big Ben FFCMH / FL Institute for Family Involvement
Conni Wells
3927 Spring Creek Highway
Crawfordville, FL 32327
(850) 926-3514
Fax: (240) 358-6542
✉cjwells@sprynet.com
✉family_voices_fl@mindspring.com

FLORIDA, LAKE WORTH ○

FOF of Palm Beach County, Inc.
C. Veree Jenkins
2328 10th Avenue, Ste. 501, No
Lake Worth, FL 33461
✉Veree_Jenkins@DCF.state.fl.us
http://communities.msn.com/FamilyHOPE

GEORGIA, ATLANTA ◆

GA Parent Support Network
Sue Smith
1381 Metropolitan Parkway
Atlanta, GA 30310
(404) 753-3858 (home)
(404) 758-4500
Fax: (404) 758-6833
✉SuSmith@mindspring.com

GEORGIA, CONYERS ○

Peach Cares Parent Support
Lisa Pace
1131 West Avenue
Conyers, GA 30012
(770) 289-0411
Fax: (770) 922-4598
✉lpacepswi@aol.com

HAWAII, KAPOLEI ○

Hawaii Families as Allies
Sharon Nobriga & Vicky Followell
P.O. Box 700310
Kapolei, HI 96709-0310
(808) 487-8785
Fax: (808) 487-0514
✉HFAllies@aol.com

IDAHO, BOISE ○

IDAHO FFCMH
Claire Kiener
1111 South Orchard, Ste. 250
Boise, ID 83705
(208) 433-8845
Fax: (208) 433-8337
In-State: (800) 905-3436
(208) 376-0971 (home)
✉ckiener@idffcmh.org
http://www.idffcmh.org/

ILLINOIS, CHAMPAIGN ○

F.A.N.S
Cassandra Baker
206 North Randolph, L.L. Ste 6
Champaign, IL 61820
(217) 356-0113
Fax: (217) 355-3166

continued on page 154

8ordinary washcloths
8disposable Comfort Bath
COMFORT
Bath
ULTRA-THICK WASHCLOTHS
8
PEEL
Hair
SHAMPOO IN A CAP
Good Housekeeping Promises

"He's my second full time job, and the most rewarding..."

"The time we spend together is precious. There's just never enough of it.

So anything that can save even a nanosecond is important to me. Bathing used to take forever!

Now we wash without soap and water. It's a comfort for us both."

Each package of Comfort Bath™ contains 8 gentle pre-moistened disposable washcloths. You can microwave them for a warm, soothing bath. Dermatologist-tested Comfort Bath has a pH that's closest to normal, healthy skin and contains aloe and vitamin E to leave skin soft and smooth. Try rinse-free shampoo and conditioner cap, too.

Comfort Bath. Take Comfort.™

www.comfortbath.com WALGREENS•CVS•OSCO•SAV ON•ECKERD•LONGS•MAY'S•MEIJER•BROOKS
FOR THE STORE NEAREST YOU, CALL TOLL-FREE 1 877 9 COMFORT

Circle #113 or visit www.eparent.com/adinfo

FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

State Organizations, Chapters & Representatives Contact List

continued from page 152

ILLINOIS, ELMHURST ◆

Illinois Federation of Families (IFF)
Diane Ledbetter
340 W. Butterfield Road, Ste. 4-B
Elmhurst, IL 60126
(618) 326-7286 (home)
(800) 871-8400
Fax: (630) 563-3014
✉dled4@shawneelink.net

ILLINOIS, LAKE VILLA ○

Parent Information Network / APO
Mary Shahbazian
P.O. Box 1088
Lake Villa, IL 60046
(847) 356-2351x219
Fax: (847) 356-2393
✉msallendale@compuserve.com

ILLINOIS, NAPERVILLE ○

CANDU Parent Group
Cathy Bozett
24W 681 Woodcrest Drive
Naperville, IL 60540

ILLINOIS, NORMAL ○

Parents Supporting Parents
Mary & Richard Hunter
910 South Adelaide
Normal, IL 61761
(309) 454-3369
Fax: (309) 454-3608

INDIANA, HIGHLAND ○

Parents Supporting Parents
Cindy Polito
9722 Parkway Drive
Highland, IN 46322
(219) 922-3822
Fax: (219) 922-3825

INDIANA, INDIANAPOLIS ◆

Indiana FFCMH
Brenda Hamilton
55 Monument Circle, Ste. 455
Indianapolis, IN 46204
(317) 638-3501 x228
Fax: (317) 638-3540
(765) 643-4357 (home)
In State: (800) 555-6424 x228
✉mhai@indy.net

INDIANA, INDIANAPOLIS ○

Families Reaching for Rainbows FFCMH
Betty Bledsoe
4701 N. Keystone Ave.
Ste 150, Rm 413
Indianapolis, IN 46250
(317) 205-8281
(317) 842-9079
Fax: (317) 205-8343
✉rainbows@kidrap.org

IOWA, ANAMOSA ◆

Iowa FFCMH
Lori Reynolds
303 West Main
P.O. Box 362
Anamosa, IA 52205
(319) 462-2187
Fax: (319) 462-6789
(319) 462-4423 (home)
✉iaffcmhdir@aol.com

KANSAS, PARSONS ○

Parent T.E.A.M.S., Inc.
Beth Engels
P.O. Box 258
1730 Belmont
Parsons, KS 67357
(316) 421-3736
Fax: (316) 421-4583
✉beth@terraworld.net

KANSAS, TOPEKA ◆

Keys for Networking, Inc.
Kansas FFCMH
Jane Adams
1301 SW Topeka Blvd.
Topeka, KS 66612
(785) 233-8732
Fax: (785) 235-6659
In State: (800) 499-8732
✉jadams@keys.org
http://www.keys.org

KENTUCKY, FRANKFORT ◆

Kentucky Partnership for Families and Children
Carol Cecil
1410 Versailles Road #6
Frankfort, KY 40601
(502) 695-5366
(502) 695-3410
Fax: (502) 695-6829
In-State: (800) 369-0533

KENTUCKY, LOUISVILLE ○

KY-SPIN, VRI
Laurie Cottrell
10301-B Deering Road
Louisville, KY 40272
(502) 937-6894
Fax: (502) 937-6464
(800) 525-7746
✉spininc@aol.com

LOUISIANA, SHREVEPORT

Louisiana FFCMH
Vee Boyd & Mark Terry
P.O. Box 4767
Shreveport, LA 71134-0767
(318) 227-2796
Fax: (318) 227-2793
✉lafofcmh@aol.com

MAINE, OXFORD ○

Western ME Parent Awareness
Cathy Lashin
P.O. Box 640
Oxford, ME 04270
(207) 743-6368
(207) 743-2681 (home)
✉clashin@megalink.net

MARYLAND, BALTIMORE

Families Involved Together
Diane Sakwa
2219 Maryland Avenue
Baltimore, MD 21218
(410) 922-0448 (home)
(410) 235-5222
Fax: (410) 235-4222
In-State: (800) 498-5551
✉diane@familiesinvolved.org

MARYLAND, COLUMBIA ◆

MD Coalition of Families for Children's MH
Jane Walker
10632 Little Patuxent
Parkway 119
Columbia, MD 21044
(410) 730-8267
Fax: (410) 730-8331
✉info@mdcoalition.org
http://www.mdcoalition.org

MARYLAND, SILVER SPRING ○

Montgomery County Chapter of FFCMH
Leah Royce
10408 Hayes Avenue
Silver Spring, MD 20902
(301) 649-7483 (home)
✉L2953@aol.com

MASSACHUSETTS, BOSTON ◆

Parent Professional Advocacy League
Donna Welles
15 Court Square #1060
Boston, MA 02108
(617) 227-2925
Fax: (617) 227-1755
In-State: (800) 537-0446
✉pal@fcsn.org

MICHIGAN, EAST LANSING ◆

Association for Children's Mental Health
Sara Way
941 Abbott Rd., Ste. P
East Lansing, MI 48823
(517) 336-7222
Fax: (517) 336-8884
Parent Line: (800) 782-0883
✉acmhinc@aol.com

MICHIGAN, KALAMAZOO ○

Michigan Association for Children w/ Emotional Disorders
Pauline Becker
321 West South Street
Kalamazoo, MI 49007
(616) 343-5896
Fax: (616) 344-4645

MICHIGAN, SOUTHFIELD ○

Michigan Association for Children w/ Emotional Disorders
Virgil Bernero
15920 W. Twelve Mile Rd. #201
Southfield, MI 48076
(248) 552-0044
Fax: (248) 552-0047

MINNESOTA, MINNEAPOLIS ○

PACER Center
Sue Abderholden
8161 Normandale Boulevard
Minneapolis, MN 55437-1044
(952) 838-9000
(800) 537-2237 (MN only)
(952) 838-0190 (TDD)
Fax: (952) 838-0199
✉sabderholden@pacer.org

MINNESOTA, ST. PAUL ○

Minnesota Association for Children's Mental Health
Deborah Saxhaug
165 Western Avenue, Ste. 2
St. Paul, MN 55102
(651) 644-7333
Fax: (651) 644-7391
In-State: (800) 528-4511
✉dsaxhaug@macmh.org

MINNESOTA, WILLMAR ○

PACT 4 Families – Family Support Network
Patty Butler & Kim Loidolt
1900 Highway 294 N.E.
Ste. 2030
Willmar, MN 56201
(320) 231-7030
Fax: (320) 231-7033
Toll free: (800) 960-7228
✉patty.butler@co.kandiyohi.mn.us
✉kim.loidolt@co.kandiyohi.mn.us

MISSISSIPPI, BAY ST. LOUIS ○

Gulf Coast Chapter FFCMH
Cheryl Rasbury
220 Bay Oaks Drive
Bay St. Louis, MS 39520

MISSISSIPPI, JACKSON ◆

Mississippi Families as Allies
Tessie B. Schweitzer, MSW
5166 Keele Street B-100
Jackson, MS 39206
(601) 969-9209 (home)
(601) 981-1618
Fax: (601) 981-1696
In-State: (800) 833-9671
✉msfaa@netdoor.com

MISSISSIPPI, PETAL ○

South Central Support Group
Ginger Sue Cooksey
P.O. Box 122
Petal, MS 39465

MISSOURI, BISMARCK ○

MO-SPAN SE Region
LuAnn Reese
505 Nevada Drive
Bismarck, MO 63624
(573) 734-2153
✉mospan3@swbell.net

MISSOURI, FLORISSANT ◆

MO-SPAN
Donna Dittrich
470 A Rue St. Francois
Florissant, MO 63031
(314) 972-0634 (home)
(314) 972-0600
Fax: (314) 972-0606
✉ddmospan@swbell.net
http://www.mo-span.org

MISSOURI, JEFFERSON CITY ○

MO-SPAN Central Region
Barbara Scheidegger
2623 Idlewood Road
Jefferson City, MO 65109
(573) 635-6186
Fax: (573) 635-6438
✉mospan2@fidnet.com

MISSOURI, KANSAS CITY ○

MO-SPAN NW Region
Pam Kingsley
5535 Oak Street
Kansas City, MO 64113
(816) 523-3249
Fax: (816) 333-6220
✉pjkingsley@Juno.com

MISSOURI, ST. CHARLES ○

Family Advocacy & Community Training (F.A.C.T.)
Audrey Yarbrough
2260 B Westone
St. Charles, MO 63303
(636) 949-2425 x11
Fax: (636) 724-3664

MONTANA, BILLINGS ◆

Family Support Network
Betty Jo Engleman
P.O. Box 21366
Billings, MT 59104
(406) 259-5931 (home)
(406) 256-7783
Fax: (406) 256-9879
✉fsntoo@aol.com

NEBRASKA , KEARNEY ○

Families CARE
Suzanne Young
4009 West 6th Avenue 65
Kearney, NE 68845
(308) 237-1102
Fax: (308) 236-7669

NEBRASKA , LINCOLN ○

Nebraska Family Support Network
Linda Liebendorfer
215 Centennial Mall South 220
Lincoln, NE 68508-1813
(402) 477-2992
Fax: (402) 477-3192
In-State: (800) 245-6081

NEBRASKA, LINCOLN ○

Healthy Families Affiliate
Patricia Blakely
315 South 9th Street, Ste. 200
Lincoln, NE 68508
(402) 441-3802
Fax: (402) 441-4872

NEBRASKA, MCCOOK ○

R.I.T.E.S. for Families
Christy Fricke
112 West C Street
McCook, NE 69001
(308) 345-3528
Fax: (308) 345-3565
(308) 278-2337 (home)
✉rites@swnebr.net

NEBRASKA , NORFOLK ○

Parent to Parent Network
Judy Domina-Schwede
P.O. Box 1402
Norfolk, NE 68702
(402) 379-2268
Fax: (402) 371-9355

NEVADA , LAS VEGAS ○

Nevada PEP, Inc.
T.J. Ingebretsen
2810 W Charleston, Ste. G-68
Las Vegas, NV 89102
(702) 388-2966 (home)
(702) 388-8899
Fax: (702) 388-2966
In-state: (800) 216-5188
✉nvpepti@aol.com

NEW HAMPSHIRE, CONCORD ○

Alliance for the Mentally Ill of New Hampshire
Linda Thomas
10 Ferry Street 314
Concord, NH 03301
(603) 225-5359
Fax: (603) 228-8848
In-State: (800) 242-6264
✉naminh@conknet.com

NEW HAMPSHIRE, LONDONDERRY ◆

Granite State FFCMH
Kathleen Abate
P.O. Box 1202
Londonderry, NH 03053-1202
(603) 785-7948
(603) 432-8302 (home)

NEW JERSEY, MEDFORD ○

Families Finding Hope
Marlene Penn / Julia Harris
8 Tudor Court
Medford, NJ 08055
(609) 714-1353
✉mpenn8@aol.com

NEW JERSEY, NEWARK ○

Statewide Parent Advocacy Network
Diane Autin
35 Halsey Street
Newark, NJ 07102
(973) 783-0203 (home)
(973) 642-8100 x105
Fax: (973) 642-8080
✉pan@bellatlantic.net

NEW JERSEY, NEW BRUNSWICK

NJ Parents Caucus
Loretta Geis
100 Bayard Street, Ste. 312
New Brunswick, NJ 08901-2165
(732) 247-3133
Fax: (732) 247-4644
✉njpc@inetmail.att.net

NEW MEXICO, ALBUQUERQUE

Parents for Behaviorally Different Children
Delfy Pena Roach
5905 Marble, NE, Ste. 8
Albuquerque, NM 87110
(505) 265-0430
Fax: (505) 255-6578
In-State: (800) 273-7232

NEW YORK, ALBANY ◆

Families Together in New York State, Inc.
Paige McDonald
15 Elk Street
Albany, NY 12207
(518) 432-0333 x12
Fax: (518) 434-6478
Info & Referral Line:
(888) 326-8644
✉pmacdonald@ftnys.org
http://www.ftnys.org

NEW YORK, ALBANY ○

Families United Network,
c/o Parsons Child and Family Center
Joan Valery
60 Academy Road
Albany, NY 12208
(518) 475-1970 (home)
(518) 426-2600
Fax: (518) 447-5234
✉jvaledry@albany.net
http://www.st-cath.org/fun.htm

NEW YORK, BATH ○

Finger Lakes Parent Network, Inc.
Patti DiNardo & Carol Pressler
25 West Steuben Street
Bath, NY 14810-1511
(716) 289-4874 (home)
(607) 776-2164
Fax: (716) 289-3501
✉edinardo@eznet.net

NEW YORK, ORANGEBURG ○

Parent Support Network
Micki Leader
175 Rutgers Road, East
Orangeburg, NY 10962
(914) 359-6090 (home)
Fax: (914) 359-6248 ✆

NEW YORK, POUGHKEEPSIE ○

Mental Health Association in Duchess County
Lynn Rogers
510 Haight Avenue
Poughkeepsie, NY 12603
(914) 473-2500
Fax: (914) 473-4870

NEW YORK, ROCHESTER ○

Monroe County FFCMH / Better Days Ahead
Debbie Bartlett
339 East Avenue, Ste. 201
Rochester, NY 14604-2615
(716) 325-3145 x16
Fax: (716) 325-3188
✉dbartlett@mharochester.org
http://www.betterdaysahead.org

NEW YORK, WYNANTSKILL ○

WITS End Family Support / Vanderhyden Hall, Inc.
Jill Sharp
P.O. Box 219
Wynantskill, NY 12198
(518) 283-3458 x15
Fax: (518) 283-3347

NORTH CAROLINA, ARDEN ○

WNC Families CAN
Jillian Wolf
P.O. Box 665
Arden, NC 28704
(828) 687-1157
Fax: (828) 687-1163
✉wncfamilies@earthlink.net

NORTH DAKOTA, BISMARCK ◆

ND FFCMH
Dave Meiers
P.O. Box 3061
Bismarck, ND 58502-3061
(701) 250-1795 ✆
✉ndkfed@btigate.com

NORTH DAKOTA, BISMARCK ○

ND FFCMH Region VII
Carlotta McCleary
P.O. Box 3061
Bismarck, ND 58502-3061
(701) 222-1223
Fax: (701) 250-8835

NORTH DAKOTA, FARGO ○

ND FFCMH Region V
Shirley Reimer
1104 2nd Ave. South
Fargo, ND 58103
(701) 235-6948
Fax: (701) 235-9923
✉ndffrg19@idet.net

NORTH DAKOTA, WIMBLEDON ○

ND FFCMH Region II
Sheri Seefried
9906 13th Street, SE
Wimbledon, ND 58492
(701) 435-2495
✉seefried@buffabrity.net

OHIO, CANFILED ○

First Ohio Chapter – FFCMH
Chrysann Mitzel
4505 Quaker Court
Canfiled, OH 44406
(330) 533-4649 (home)
(330) 726-9570
Fax: (330) 726-9031

OHIO, CINCINNATI ○

OH Family Organization for Children's Mental Health, Inc.
Terre Garner & Pamela Harris
11647 Hamlet Road
Cincinnati, OH 45240-1907
(513) 851-9884

OHIO, CLEVELAND ○

Positive Education Program
Linda Downing
3100 Euclid Avenue
Cleveland, OH 44115
(216) 361-4400
Fax: (216) 361-8600
✉pepgen@pepcleve.org
http://www.pepcleve.org

OHIO, STOW ○

Parent Support Network – You Are Not Alone FFCMH
Sue Wilson
2457 E. Norman Drive
Stow, OH 44224
(330) 686-2617
✉swilson6@neo.rrcom

OKLAHOMA, OKLAHOMA CITY ○

FFCMH in OK, Inc.
Lyn Thoreson
P.O. Box 32255
Oklahoma City, OK 73123
(405) 373-3300
Fax: (405) 373-3012
✉fedoffamilies@aol.com

OKLAHOMA, OKLAHOMA CITY ○

OK AMI
Karen Landolfi
500 North Broadway, Ste. 100
Oklahoma City, OK 73102
(405) 230-1901
Fax: (405) 230-1903

OKLAHOMA, TULSA ○

Tulsa Unified FFCMH (T.U.F.F.)
Sherry Hamby
1022 North Harvard
Tulsa, OK 74115
(918) 838-8033
✉sherryscoobydoo@aol.com

OREGON, SALEM ◆

Oregon Family Support Network
Callie Schlippert
P.O. Box 13820
Salem, OR 97309-1820
(503) 697-1808 (home)
(503) 581-2047
Fax: (503) 581-4841
✉ofsn@open.org

PENNSYLVANIA, PHILADELPHIA ◆

Parents Involved Network of Pennsylvania
Glenda Fine
1211 Chestnut Street 11th Floor
Philadelphia, PA 19107
(215) 751-1800 x214
Fax: (215) 636-6300
In-State: (800) 688-2446 x214
✉pin@mhasp.org
http://www.pinofpa.org

PUERTO RICO, SAN JUAN

Linda Landrau
El Vedado
430 Paoli Street, 2nd Floor
San Juan, PR 00918
(787) 250-0453 (home)

RHODE ISLAND, WARWICK ○

Parent Support Network
Cathy Ciano
400 Warwick Ave., Ste. 12
Warwick, RI 02888
(401) 267-0065 (home)
(401) 467-6855
Fax: (401) 467-6903
In-State: (800) 483-8844

RHODE ISLAND, WESTERLY ○

Parent Support Network
Nancy Anzoli
4 Shore Road
Westerly, RI 02891
(401) 348-8816 (home)

SOUTH CAROLINA, COLUMBIA ○

Federation of Families of SC, MHASC
Marcia Davis Taylor
1823 Gadsden Street
Columbia, SC 29201
(803) 779-5363
Fax: (803) 779-0017
In-State: (800) 375-9894
✉fedfamSC@yahoo.com

SOUTH DAKOTA, KYLE ○

Oglala Lakota Tiwahe Advocacy Group
Willa Quick Bear
P.O. Box 391
Kyle, SD 57752
(605) 867-2883
Fax: (605) 867-2884

SOUTH DAKOTA, SIOUX FALLS

Anita Otten
2609 South Elmwood Avenue
Sioux Falls, SD 57105
(605) 336-2609 (home)

SOUTH DAKOTA, WAKPALA

Manaja Unijinca Hill
P.O. Box 92
Wakpala, SD 57658
(605) 845-7986 (home)

TENNESSEE, NASHVILLE ○

TN Voices for Children, Inc.
Charlotte Bryson
1315 8th Avenue, South
Nashville, TN 37203
(615) 269-7751
Fax: (615) 269-8914
In-State: (800) 670-9882
E-Mail: tvc@tnvoices.org
http://www.tnvoices.org

TEXAS, AUSTIN ◆

Texas FFCMH
Patti Derr
7701 No. Lamar, Ste. 501
Austin, TX 78752
(512) 451-3191
Fax: (512) 451-8302
In-State: (800) 860-6057
✉Patti_Derr@tmhc.org

TEXAS, AUSTIN ○

Central Texas FFCMH
Mattie Dixon
6418 Orange Blossom
Austin, Texas 78744
(512) 282-7126 (home)
Fax: (512) 282-5817
✉mattie_Dixon@hotmail.com

FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

State Organizations, Chapters & Representatives Contact List

TEXAS, AUSTIN ○

FFCMH
Stephany Bryan
1717 West 10th Street
Austin, TX 78703
(512) 804-3174
Fax: (512) 804-3169
(512) 416-0840 (home)
✉Stephany.bryan@atcmhmr.com

TEXAS, AUSTIN ○

Texas Mental Health Consumers
Mike Halligan
7701 North Lamar, Ste. 500
Austin, TX 78752
(512) 451-3191
Fax: (512) 451-8302
(800) 860-6057
✉Mike_Halligan@tmhc.org

TEXAS, DALLAS ○

Dallas FFCMH
Susan Rogers
2629 Sharpveiw Lane
Dallas, TX 75228
(214) 320-3516 (home)
(214) 320-1825
Fax: (214) 320-3750
✉dallasffcmh@earthlink.net

TEXAS, HOUSTON ○

Harris County FFCMH
Sharon Brown
4103 Wild Acres Drive
Houston, TX 77072
(713) 970-4417
Fax: (281) 530-3938
Pager: (713) 602-7733
✉sbrown1130@aol.com

TEXAS, HOUSTON ○

Southeast Houston FFCMH
Sandra Sacallan
6515 Hillcroft Street, Apt 441
Houston, TX 77081
(713) 777-0195

TEXAS, JASPER ○

Deep East Texas FFCMH
Roann Brown
P.O. Box 2294
Jasper, TX 75951
(409) 384-7326 or
(409) 383-310[illegible]
Fax: (409) 489-0176
✉families@jas.net

TEXAS, SANTA FE ○

Gulf Coast FFCMH
Cherie Manis
Drawer O
Santa Fe, TX 77510
(800) 839-8876
Fax: (409) 756-8326
(409) 925-5547 (home)
Pager: (409) 643-3040
✉ParentCnt@aol.com

TEXAS, SHERMAN ○

Grayson County FFCMH
Pat Owens & Terri Hopper
4820-C Highgrove
Sherman, TX 75090
Pat's Home: (903) 893-3742
Terri's Home: (903) 893-6496
Fax: (903) 883-3742 ©
✉1: Thop1230@aol.com
✉2: patoadv@texoma.net

TEXAS, TROY ○

Bell County Chapter FFCMH
Don & Sandy Donahue
10707 Pendleton Troy Road
Troy, TX 76579
(254) 938-2307
Fax: (254) 938-2431
✉Gerskd@vvm.com

UTAH, SALT LAKE CITY ○

Allies with Families
Pat Baker
1792 Lincoln Lane 2
Salt Lake City, UT 84123
(801) 293-7458
Fax: (801) 292-8777
✉awfamilies@uswest.net

VERMONT, MONTPELIER ○

Vermont FFCMH
Pamela Dow
P.O. Box 607
Montpelier, VT 05601-0607
(802) 223-4917
Fax: (802) 828-2159
Families only: (800) 639-6071
✉vffcmh@earthlink.net

VIRGINIA, ALEXANDRIA ○

Families First of Alexandria, Inc.
Nancy McCormick
817 Little Street
Alexandria, VA 22301
(703) 548-2477 (home)
Fax: (703) 548-0539
✉FAM1stalex@aol.com

VIRGINIA, MECHANICSVILLE ◆

PACCT
Joyce Kube
7286 Ewell Circle
Mechanicsville, VA 23111
(804) 559-6833
Fax: (804) 559-6835

VIRGINIA, RICHMOND ○

Parent Resource Network
Valerie Burrell-Muhammad
909 Chimborazo Boulevard
Richmond, VA 2[illegible]
(804) 222-0455
Fax: (804) 222-0581

WASHINGTON, EVERETT ○

Everett Village Moms FFCMH
Pacific Crest Family Support
Connie Buckley
2731 Wetmore Avenue,
Ste. 220
Everett, WA 98201-3581
(425) 252-7716
(425) 258-1730 (home)

WASHINGTON, EVERETT ○

The Family Connection
Carla Hall
2722 Colby, Ste. 104
Everett, WA 98201
(425) 388-7400
Fax: (425) 259-1444
✉ppmbb@aol.com

WASHINGTON, RENTON ◆

Federation of Families
Marilynn Williams
2832 Sunset Lane, NE
Renton, WA 98056
(425) 277-0426
Fax: (425) 277-5010
✉marilynn@rocketmail.com

WASHINGTON, RENTON ○

Renton Children's Inalienable Rights to Services Chapter of Federation of Families
Tammi Keener
16405 S.E. Maple Valley
Hwy. #20
Renton, WA 98058
(425) 235-7316
✉peanut67@prodigy.net

WASHINGTON, SEATTLE ○

Seattle Parent Advocacy Network
Robin Belz
2142 10th Avenue, W
Seattle, WA 98119
(206) 298-9626
Fax: (206) 284-7843
✉rbelz@seattlechildrenshome.org

WASHINGTON, TAKOMA ○

Tacoma Chapter of FOF
Claudia M. Muhammad
5918 26th Street, NE
Tacoma, WA 98422
(253) 927-1620

WEST VIRGINIA, CLARKSBURG ○

United Summit Parent Center
Pam Harper
6 Hospital Plaza
Clarksburg, WV 26301
(800) 786-6486
Fax: (304) 623-2989

WEST VIRGINIA, HUNTINGTON ○

MSPACN – Southern Region II
Kim Lackey
P.O. Box 301
Lenore, WV 25676
(304) 752-9080
Fax: (304) 526-9337
Toll free: (877) 472-3197
✉klackey@intelos.net
http://www.mspcan.org

WEST VIRGINIA, INSTITUTE ○

MSPCAN – Northern Region II
Roxana Carnes
c/o Shawnee Hills
141 Academy Drive
Institute, WV 25112
(304) 766-6580
Fax: (304) 766-6581
Toll free: (877) 320-0533
✉roxana@ezwv.com
http://www.mscan.org

WEST VIRGINIA; PHILIPPI ○

Barbour County You Are Not Alone Support Group
Tina Swaney
109 Maple Avenue
Philippi, WV 26416
(304) 457-1889
Fax: (304) 457-2693
✉BCFRN@access.mountain.net

WEST VIRGINIA, WHEELING ◆

Mountain State Parent Children & Adolescent Network
Teri Toothman
1143 Main Street, Ste. 1-D
Wheeling, WV 26003-0906
(304) 233-3289 (home)
(304) 233-5399
Fax: (304) 233-3847
In-State: (800) 244-5385
✉ttoothman@mspcan.org

WISCONSIN, MADISON ◆

Wisconsin Family Ties
Maggie Mezera
16 North Carroll Street #640
Madison, WI 53703
(608) 267-6888
Fax: (608) 267-6801
In-State: (800) 422-7145

WISCONSIN, MILWAUKEE ○

Families United of Milwaukee
Margaret Jefferson
9501 Waterton Plank Road
Milwaukee, WI 53226
(414) 257-6857
Fax: (414) 257-7575

WISCONSIN, MILWAUKEE ○

W.A.T.C.H
Zelodius Brown
First Love Community
Outreach Center
429 W.N. Avenue
Milwaukee, WI 53212
(414) 263-3375
Fax: (414) 263-1148

WYOMING, CASPER ○

UPLIFT
Peggy Nikkel
UPLIFT Casper Office
145 So. Durbin, Ste. 204
Casper, WY 82601
(307) 232-8944
Fax: (307) 232-8945
Cell Phone: (307) 267-0693
✉pnikkel@wyoming.com
http://www.uplift-wyoming.com

WYOMING, CHEYENNE ○

UPLIFT
Same Org. as above
Main mailing address for WY
Carla Schroeder
P.O. Box 664
Cheyenne, WY 82003-0664
(800) UPLIFTS
(307) 778-8686
Fax: (307) 778-8681 ©

VOCATIONAL REHABILITATION PROGRAMS

Vocational rehabilitation assists people with disabilities in preparing for, beginning, and keeping employment. One of the oldest programs in which state funds are matched by federal funds, vocational rehabilitation began in 1920, with the passage of the Civilian Vocational Rehabilitation Act, which encouraged states to provide rehabilitation services to disabled veterans. Today, vocational rehabilitation programs operate under the Rehabilitation Act of 1973 and its subsequent amendments. Following is a listing of state vocational rehabilitation services.

USING THIS DIRECTORY

When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol ✉ (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

Alabama Department of
Rehabilitation Services (ADRS)
Human Resources Department
2129 E. South Blvd.
PO Box 11586
Montgomery, AL 36116-2455
(800) 441-7607
(334) 281-8780
(334) 281-1973 (fax)
✉webinfo@rehab.state.al.us
http://www.rehab.state.al.us/vrs.html

ALASKA

Alaska Vocational Technical Center
PO Box 889
809 2nd Ave.
Seward, AK 99664
(800) 478-5389
(907) 224-4152 (Admissions Office)
(907) 224-4143 (fax)
http://www.educ.state.ak.us/AVTEC

ARIZONA

Arizona Rehabilitation
Services Adminstration
10640 N. 28th Dr., Ste. B 106
Phoenix, AZ 85029
(602) 789-9129
(602) 789-9309 (fax)
http://www.de.state.az.us/rsa/

ARKANSAS

Arkansas Rehabilitation Service
1616 Brookwood Dr.
PO Box 3781
Little Rock, AR 72203
(501) 296-1600
(501) 296-1655 (fax)
(501) 296-1669 (TDD)
(800) 285-1121 (Voice Relay)
(800) 285-1131 (TDD)
http://www.arsinfo.org/

CALIFORNIA

California Department
of Rehabilitation
2000 Evergreen St.
PO Box 944222
Sacramento, CA 95815-3832
(916) 263-8981
(916) 263-7477 (TDD)
✉suggest@dor.ca.gov
http://www.rehab.cahwnet.gov/

COLORADO

Colorado Division of
Vocational Rehabilitation
2211 W. Evans Ave., Bldg. B
Denver, CO 80223
(720) 884-1234
(720) 884-1235
✉debbie.powell@state.co.us
http://www.cdhs.state.co.us/ods/dvr/index.html

CONNECTICUT

Department of Social Services
Bureau of Rehabilitation Services
25 Sigourney Street-11th Floor
Hartford, CT 06106
(800) 537-2549 (voice)
(860) 424-4844 (voice)
(860) 424-4839 (TDD/TTY)
✉judith.moeckel@po.state.ct.us

DELAWARE

Delaware Division of
Vocational Rehabilitation
4425 N. Market St.
PO Box 9969
Wilmington, DE 19089-0969
(302) 761-8275 (voice/TDD)
(302) 761-6611 (fax)
http://www.delawareworks.com/divisions/dvr/welcome.htm

FLORIDA

Florida Vocational
Rehabilitation Services
Building A
2002 Old St. Augustine Rd.
Tallahassee, FL 32399-0696
(850) 488-0059
(800) 451-4327 (Voice/TDD)
(850) 921-2959 (fax)
✉rhodenv@vr.fdles.state.fl.us
http://www.fim.edu/doe/bin00058/vr_hp1.htm

GEORGIA

Georgia Vocational
Rehabilitation Program
2 Peachtree St., NW, 35th Floor
Atlanta, GA 30303-3142
(404) 657-3000 (voice or TDD)
✉defennel@dol.state.ga.us
http://www.vocrehabga.org/

HAWAII

Vocational Rehabilitation and
Services for the Blind
PO Box 339
Honolulu, HI 96809
http://www.ehawaii.gov/

IDAHO

Division of Vocational
Rehabilitation
PO Box 83720
650 W. State St., Rm. 150
Boise, ID 83720-0096
(208) 334-3390 (voice/TDD)
(208) 334-5305 (fax)
✉bthompson@idvr.state.id.us
http://www2.state.id.us/idvr/

ILLINOIS

IL Department of Human Services
Office of Vocational
Rehabilition Services
100 S. Grand Ave. E., 3rd Floor
Springfield, IL 62762
(217) 785-0234
(217) 558-4270 (Fax)
(800) 843-6154
(800) 447-6404 (TDD)
✉ors@dhs.state.il.us
http://www.state.il.us/agency/dhs/orsfsnp.html

INDIANA

Indiana Family and Social
Services Administration
402 West Washington Street
Room W 453
PO Box 7083
Indianapolis, IN 46207-7083
(800) 545-7763
(317) 232-1319
http://www.isdd.indiana.edu/~cedir/vocrehab.html

IOWA

Iowa Division of Vocational
Rehabilitation Services
510 E. 12th St.
Des Moines, IA 50319
(515) 281-4311
(800) 532-1486 (Voice/TDD)
http://www.dvrs.state.ia.us

KANSAS

Kansas Department of Social
and Rehabilitation Services
915 SW Harrison, Rm. 630 N.
Topeka, KS 66612
(785) 296-3959
(785) 296-2173 (fax)
http://www.srskansas.org

KENTUCKY

Kentucky Department of
Rehabilitation Services
209 St. Clair St.
Frankfort KY, 40601
(800) 372-7172
(502) 564-4440
(888) 420-9874
(502) 564-6742
http://kydvr.state.ky.us/index1.htm

LOUISIANA

Louisiana Rehabilitation Services
8225 Florida Blvd.
Baton Rouge, LA 70806
(800) 737-2958
(225) 925-4131
(225) 925-4184 (fax)
✉chymel@lrs.state.la.us
http://www.dss.state.la.us/offlrs/html/vocational_rehabilitation.html

MAINE

Bureau of Rehabilitation Services
150 State House Station
Augusta, ME 04333-0150
(207) 624-5950
(800) 698-4440 (TDD)
(207) 624-5980 (fax)
http://www.state.me.us/rehab/

MARYLAND

Maryland Rehabilitation Center
2301 Argonne Dr.
Baltimore, MD 21218-1696
(410) 554-9385
(410) 554-9411 (TDD)
(410) 554-9412 (fax)
http://www.dors.state.md.us

MASSACHUSETTS

MA Rehabilitation Commission
Fort Point Place
Suite 600
27 Wormwood Street
Boston, MA 02210-1616
(800) 245-6543 (Voice/TTY)
(617) 204-3600
(617) 727-1354 (fax)
http://www.state.ma.us/mrc

MICHIGAN

Michigan Rehabilitation Services
201 N. Washington Sq., 4th Floor
PO Box 30010
Lansing, MI 48909
(517) 373-3390
(517) 373-0565 (fax)
(800) 605-6722 (toll free)
(888) 605-6722 (toll free, TTY)
✉blodgerk@state.mi.us
http://www.mrs.mjc.state.mi.us

MINNESOTA

Department of Economic Security
Rehabilitation Services Branch
390 N. Robert St.
St. Paul , MN 55101
(651) 296-9981
(800) 328-9095
(651) 296-3900 (TDD)
(800) 657-3973 (TDD)
(651) 297-5159 (Fax)
✉Paul.Bridges@state.mn.us
http://www.mnwfc.org/rehab/vr/main_vr.htm

MISSISSIPPI

Mississippi Department of
Rehabilitation Services
PO Box 1698
Jackson, MS 39215-1698
(800) 443-1000
(601) 853-5100
(601) 853-5758 (fax)
http://www.mdrs.state.ms.us

MISSOURI

Missouri Division of Vocational
Rehabilitation
3024 Dupont Circle
Jefferson City, MO 65109-0525
(877) 222-8963
(573) 751-3251
(573) 751-0881 (TDD)
(573) 751-1441 (fax)
✉kkendle@vr.dese.state.mo.us
http://www.vr.dese.state.mo.us/vr/co/VRWebsite.nsf

MONTANA

State of Montana SRS
111 Sanders, Ste. 307
PO Box 4210
Helena, MT 59604-4210
(877) 296-1197 (toll free)
(406) 444-2590 (voice/TDD)
(406) 444-3632 (fax)
http://www.dphhs.state.mt.us/dsd/index.htm

NEBRASKA

Nebraska Department of Education
Vocational Rehabilitation
5143 S. 48th St.
Lincoln, NE 68516-2299
(877) NE REHAB (NE only)
(800) 472-3382
(402) 471-3231
(402) 471-6309 (fax)
http://www.vocrehab.state.ne.us

NEVADA

State of Nevada Department of
Employment, Training, and
Rehabilitaiton
Rehabilitation Division
500 East Third Street
Carson City, NV 89713
(775) 684-4040
(775) 684-8400 (TDD)
(775) 684-4184 (fax)
http://detr.state.nv.us/

NEW HAMPSHIRE

New Hampshire
Department of Education
Division of Adult Learning
and Rehabilitation
78 Regional Drive
Concord, NH 03301-8508
(800) 299-1647
(603) 271-3471 (TDD)
(603) 271-7095 (fax)
http://www.state.nh.us

NEW JERSEY

New Jersey Division of Vocational
Rehabilitation Services
135 E. State St.
PO Box 398
Trenton, NJ 08625-0398
(609) 292-5987
(609) 292-2919 (TDD)
(609) 292-8347 (fax)
✉dvradmin@dol.state.nj.us
http://www.state.nj.us/labor/dvrs/dvr.html

NEW MEXICO

Division of Vocational
Rehabilitation
435 St. Michael's Dr., Bldg. D
Santa Fe, New Mexico 87505
(800) 224-7005
(505) 954-8500
(505) 954-8562 (fax)
✉SKelley@state.nm.us
http://public.dvrgetsjobs.com/

NEW YORK

NY State Education Department
Vocational & Educational Services for
Individuals with Disabilities (VESID)
1606 One Commerce Plaza
Albany, NY 12234
(800) 222-5627
(518) 474-2714
(518) 486-4154 (fax)
✉VESIDSPE@mail.nysed.gov
http://web.nysed.gov/vesid

NORTH CAROLINA

North Carolina Division of
Vocational Rehabilitation Services
2801 Mail Service Center
Raleigh, NC 27699-2801
Location: 805 Ruggles, Raleigh
(919) 733-3364
(919) 733-7968 (fax)
http://www.dhhs.state.nc.us/docs/divinfo/dvr.htm

NORTH DAKOTA

ND Department of Human Services
Disability Services Division
Vocational Rehabilitation Ste. 1B
600 South Second Street
Bismarck, ND 58504-5729
(701) 328-8950
(701) 328-8968 (TDD)
(701) 328-8969 (fax)

OHIO

Ohio Rehabilitation
Services Commission
400 E. Campus View Blvd.
Columbus, OH 43235-4604
(800) 282-4536 (Voice/TDD in OH)
(614) 438-1200 (Voice/TDD)
http://www.state.oh.us/rsc/index2.html

VOCATIONAL REHABILITATION PROGRAMS

OKLAHOMA

Oklahoma Department of Rehabilitation Services
3535 NW 58th St., Ste. 500
Oklahoma City, OK 73112
(800) 845-8476
(405) 951-3400 (Voice/TDD)
(405) 951-3529 (fax)
✉drspiowm@onenet.net
http://www.okrehab.org/

OREGON

Oregon Department of Human Services
500 Summer St., E 47
Salem, OR 97310-1066
(503) 945-5601
(503) 945-5928 (TDD)
(503) 373-7032 (fax)
http://www.vrd.hr.state.or.us/

PENNSYLVANIA

Department of Labor and Industry
Office of Vocational Rehabilitation
909 Green Street
Harrisburg, PA 17102
(800) 442-6351
✉OVR@dli.state.pa.us
http://www.dli.state.pa.us/landi/cwp/view.asp?a=128&Q=168255

RHODE ISLAND

RI Department of Human Services
Office of Rehabilitation Services
40 Fountain Street
Providence, RI 02903
(401) 421-7005 (Voice)
(401) 421-7016 (TDD)
(401) 222-3574 (Fax)
(401) 272-8090 (Spanish)
(401) 272-7990 (Cambodian)
http://www.ors.state.ri.us/

SOUTH CAROLINA

South Carolina Vocational Rehabilitation Department
State Office Bldg.
1410 Boston Ave.
PO Box 15
W. Columbia, SC 29171-0015
(803) 896-6500
http://www.scvrd.net

SOUTH DAKOTA

SD Rehabilitation Services
Hillsview Plaza
3800 E. Hwy 35
c/o 500 East Capitol
Pierre, SD 57501-5070
(605) 773-3195
(605) 773-5483 (fax)
✉eric.weiss@state.sd.us
http://www.state.sd.us/dhs/drs/

TENNESSEE

Department of Human Services
Division of Vocational Rehabilitation
400 Deaderick Street
Citizens Plaza
Nashville, TN 37248
(615) 313-4700 (DHS home)
(800) 628-7818 (Toll free)
(615) 741-4737 (VR home)
http://www.state.tn.us/humanserv/

TEXAS

Texas Rehabilitation Commission
4900 N. Lamar Blvd.
Austin, TX 78751
(800) 628-5115 (client svcs. only)
(512) 424-4000

UTAH

Office of Rehabilitation
250 E. 500 South
Salt Lake City, UT 84111-3272
(801) 538-7530
(800) 473-7530
(801) 538-7522 (fax)
http://www.usor.state.ut.us/

VERMONT

Division of Vocational Rehabilitation
103 South Main Street
Osgood II Building
Waterbury, VT 05671-2303
(802) 241-2186 (Voice/TTY)
(802) 241-1455 (TTY Next Talk)
http://www.dad.state.vt.us/DVR/

VIRGINIA

Department of Rehabilitative Services
8004 Franklin Farm Drive
PO Box K300
Richmond, VA 23288-0300
(804) 662-7001 (Voice)
(804) 662-9532 (fax)
(804) 662-9040 (TDD)
(800) 552-5019 (Voice)
(800) 464-9950 (TDD)
✉Drs@drs.state.va.us
http://www.vadrs.org/vocational_rehabilitation.htm

WASHINGTON

Department of Social and Health Services
Division of Vocational Rehabilitation
DVR State Office - Lacey
Mailing Address: PO Box 45340
Olympia, WA 98504
Street Address: 612 Woodland Sq. Loop SE, Lacey, WA 98503-1044
(360) 438-8000 (Voice/TDD)
(800) 637-5627 (Voice/TDD)
(360) 438-8007 (fax)
http://www-app2.wa.gov/dshs/dvr/index.htm

WEST VIRGINIA

Division of Rehabilitation Services
State Capitol
PO Box 50890
Charleston, WV 25305-0890
(800) 642-8207
(304) 766-4601
http://www.wvdrs.org

WISCONSIN

Department of Workforce Development (DWD)
Division of Vocational Rehabilitation
2917 International Lane
Suite 300
PO Box 7852
Madison, WI 53707-7852
(608) 243-5600 (Voice)
(888) 877-5939 (TTY)
(800) 442-3477 (Toll Free)
(608) 243-5680 (fax)
(608) 243-5681 (fax)
http://www.dwd.state.wi.us

WYOMING

WY Department of Employment
Vocational Rehabilitation Services
1100 Herschler Building
Cheyenne, WY 82002
(307) 777-7389
(307) 777-7672
http://wydoe.state.wy.us/doe.asp?ID=5

THE MELMARK SCHOOL

2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Our approved private day and boarding school serves children ages 5-21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Aquired Brain Injuries
- Celebral Palsy
- Mental Retardation
- Neurological Disorders

Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

We Offer Your Child:

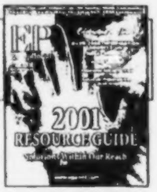
- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK Ext. 636 or email admissions@melmark.org

Circle #92 or visit www.eparent.com/adinfo

EDITORIAL INDEX 2001

JANUARY
Resource Guide



Editor's Desk 8
National Resources for Specific Disabilities 22
Matching Resources 59
Parent to Parent Programs 61
Parent Training & Information Centers 66
Mental Health Resources 72
University Affiliated Programs 75
Alliance for Technology Access Centers 77
State Assistive Technology Programs 79
Assistive Technology Consortium 82
Adaptive Recreation Organizations 87
Children's Hospitals 91
Title V 105
Exceptional People Awards 115
ADA Projects 124
Early Intervention 125
Federal & Federally Funded Information Resources 130
National Information & Advocacy Resources 132
WE MOVE 135
State Directors of Special Education 146
New Products 148
Managed Care 149
Family Voices State Contact List 151
Search & Respond Index 2000 153
P&As—State Protection and Advocacy Agencies for Persons with Developmental Disabilties, Mental Illness and the Client Assistance Programs 154
EXCEPTIONAL PARENT LIBRARY 157
Vocational Rehabilitation PROGRAMS 169
2000 Exceptional Parent Index 172
Canadian Resources 179
DIRECTORY OF PRODUCTS AND SERVICES 197
MARKETPLACE 207
PRODUCT SHOWCASE 210

FEBRUARY
Early Childhood

EP
EARLY CHILDHOOD

19 Daycare for a Child with a Disability: Who Is Fighting for You?
by Gale Jurasek
Although the Americans with Disabilities Act (ADA) prohibits discrimination based on disability, parents of children with special needs are often faced with this problem when seeking daycare.

24 Reader's Talk
Our readers share their experiences of searching for inclusive daycare.

34 The Benefits of Early Intervention
by Marie Baughman
A parent shares her experience with early intervention.

38 WCD Scrapbook
A review in pictures of the 2000 World Congress & Exposition on Disabilities.

52 Special Report: Parents as Partners in the Medical Home, Part 5
by Karen Burstein, PhD, and Tanis Bryan, PhD
The Family-Centered Medical Bill of Rights

62 Family Circle: Support for Parents
Tips for relieving parent stress.

66 La Fundación John Langdon Down , A.C.
This organization, based in Mexico, educates and supports children with Down syndrome and their families.

67 Picky Eater? Don't Give Up ... Yet
How to introduce new foods to your finicky child's diet.

MARCH
Medical Research Update

24 Pediatric Clinical Trials
by Rebecca Clay
Testing new medications on adults is required for drug approval by the FDA. But what are we doing to ensure that these medications are safe for our children?

30 Never Give Up Hope
by Joe and Marlene Vechina
A family leaves no stone unturned to find treatment for their son with Wilson's disease.

42 Cyber Summer Camp
by Lucinda M. O'Neill
CAST's Internet camp keeps kids busy during the long days of summer.

46 Happy Camping
by Jacqueline Gieri
"It is so exciting for the campers not to be the outsiders for once."

50 HASC Summer Program
A blend of school and camp, HASC keeps children with multiple and severe disabilities from falling behind academically during summer, and at the same time, involved in much-needed fun, and recreation.

56 Camping out, Fitting in
by Kerry Pianoforte
Teens with physical disabilities discover a lot about themselves at the Shake-a-Leg camp.

59 Princeton Language & Speech Center
by Lauren Agoratus
Finally, a mother finds a camp for her daughter, who has both behavioral challenges and a medical condition.

60 Camp Loyaltown
by Sarah Bernstein
A little sister with developmental disabilities returns home from summer camp with new interests, new skills, and a big sister takes notice.

APRIL
Mobility

28 Nuts and Bolts of Seating Systems
by Ginny Paleg
Advice on building a seating system from the bottom up.

30 Hope's Magic: Making Mobility a Reality
by Tonya Kimball
A camp for children with physical disabilities gets kids moving.

39 What You Should Know About the First Wheelchair
by Louise Kinross
Getting mobile is important in a child's development, and picking the right chair needs to be an informed decision.

48 Taking Care of Their Own
by Sgt. Angela C. Strong, USMC
A Marine sergeant and exceptional parent in need learns the meaning of the word "brotherhood."

54 Wheels for Children
by Cathy Mulholland, OTR
Two organizations bring mobility equipment to children in need around the world.

58 Recreational Therapy—Family Style
by Ann Allen
A mother of two children, one with a disability and one without, serves up a laundry list of outdoor activities a family can do together, without bulging the budget.

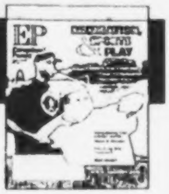
62 TEAMWORK— The Name of the Game at the Miami Children's Hospital Dan Marino Center
A pro-football legend gives back to the community.

67 Appealing Insurance Rejections
by Michelle L. Lange; OTR, ABDA, ATP
A well-worded letter of medical necessity from the rehabilitation team can make insurance companies think twice about denying coverage for a back-up wheelchair.

94 Promoting Health for Individuals With Mental Retardation
Special Olympics is spearheading an initiative to ensure that the healthcare needs of people with mental retardation are being met.

EDITORIAL INDEX 2001

MAY Recreation Sports & Play



20 SACC—Structured Athletics for Challenged Children
by Kim Wise
A sports program that gets all kids playing!

26 2001 Special Olympics World Winter Games
Showcasing a "can do" attitude on the global stage.

32 "It Can Be Done"
by Richard J. Young
A father tells how karate helped his son deal with his cerebral palsy.

34 Directory of Adaptive Recreation Organizations

36 The Ultra Stretch
by Christine Stopka, PhD, ATC/L, CSCS
A virtually effortless stretching technique that gives immediate results.

40 Navy Run Jump 'n' Throw Provides Inclusion for All Kids
by Jim Santos
This program allows young people with disabilities to participate in competitive sports with peers in school. Includes instructional tips for coaches and peers.

43 A New Light in Kaspi
by Darcy Kiefel
Young people with disabilities from an orphanage in Georgia (former Soviet republic) gain new insight learning to ski.

44 Don't Try This at Home!
by David Chamalian
Extreme Mike, a man of adventure, shows the world and his family that his disabilities pose no barriers to living his life on the edge.

47 Theater of Dreams: Showcasing the Talents of People with Disabilities
by Joel M. Levy, DSW
The YAI Players take the stage in performances of poetry, song, and dance.

52 Making Beautiful Music
by Karen E. Zielinski, OTR/L
You don't have to be a virtuoso—tickling the ivories can provide limitless opportunities for fun and learning.

55 The Water's Edge: A Story of Friendship and One Family's Battle Against MS
by Joseph M. Valenzano Jr., President, CEO & Publisher of EP magazine

71 Levels of Inclusion
by Therese M. Abrams
Tips on determining whether a group or program can provide an inclusive experience for your child.

JUNE Technology in Education

32 Thinking Readers–Helping Students Take Charge of Their Learning
by Lucinda M. O'Neill
A computer-supported learning strategy that integrates literature and reading comprehension software and student-teacher dialogue.

36 Working Together: People with Learning Disabilities and Computer Technology by DO-IT
Adaptive computer hardware and software to assist individuals with LDs in furthering their academic and career goals.

40 Hands On-Hands Off
by Deanna Lang
COTA/L Assistive computer technology for individuals with limited upper body strength.

44 Software for Learning, Part One: Choosing What's Best for Your Child
by James W. Forgan, PhD and Roberta K. Weber, EdD
With the Individualized Special Needs Software Evaluation Instrument, parents and educators can decide if a specific computer software program will be successful.

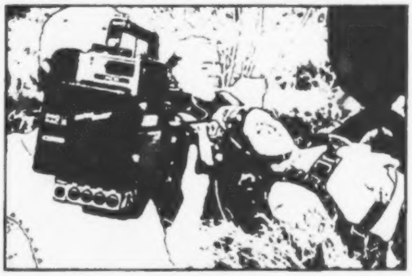
48 EP Survey—Top 5 Disability Sites
by Keith Hersch
Introducing a new column. This month's survey asks readers to send in a list of their "Top 5 Disability Web sites."

54 Helpful Hints for Getting Assistive Technology Devices and Services Through Your School District
by Pennsylvania's Initiative on Assistive Technology (PIAT).

60 Welcome to the World of IEPs–Ideas for Successfully Navigating the IEP Process
by Christina Goldstone
A mother shares her experience with her daughter's Individualized Education Plan (IEP):

65 Moving On
by Rich Kenney, MSW
The Foundation for Blind Children makes the transition to public schools easier for its young graduates and their parents.

70 Underwater Discovery
by David Chamalian
Scuba diving opens up a whole world to people of all ages and abilities.



76 Hitting the Road
by Gale Jurasek
John Keating, the father of a son with autism, is cycling across the US to raise awareness and fund research.

JULY Adolescence & Transitioning

20 Exceptional Parent's 30th Anniversary, Part II
We continue to highlight the thoughts of parents and professionals who care for children with disabilities, their opinions on the most important changes of the past three decades, and their impressions on what the future holds.

37 Driver's Education
by Randy M. Williams
A father explains why his daughter with ADHD should be allowed to get her driver's license.

40 Work-Based Learning: Students with Disabilities Succeeding in Education and Employment
by Michael Richardson
Tips for high school students on how to make themselves more attractive to potential employers.

46 Trying Their Wings: Youth with Disabilities Soar on Their Own
by Louise Kinross
A university-based program designed to teach young adults with physical disabilities some basic independence skills before heading off to college.

50 If Life Is a Journey, Make it a Joyride
by Rick Enright, BA, MSW
Advice to young people with physical disabilties on how to understand their bodies and achieve greater independence as a result.

52 High School and Beyond
by M. Sherril Moon, EdD, Meg Grigal, PhD, and Debra Neubert, PhD
How some alternative programs in Maryland for students aged 18 to 21 are providing special education services in settings other than high schools.

58 On Equal Ground
by Natalie Abbott
This teenager with Moebius syndrome talks about how her leadership qualities, NOT her disability, helped earn her a post with the California Governor's Committee for Employment of Disabled Persons' Youth Leadership Forum.

60 Software for Learning, Part 2: Choosing What's Best for Your Child
by James W. Forgan, PhD, and Roberta K. Weber, EdD
How to evaluate the utility of software for elementary-age children with learning disabilities, behavior disorders, or mild mental retardation.

94 State Developmental Disabilities Councils Directory
An updated listing of Developmental Disabilities Councils by state and US Territory.

AUGUST Healthcare

12 The Crisis in the Direct Support Professional Workforce
Finding, Keeping, and Training DSPs
by Amy Hewitt, PhD

26 It's 1 am, Do You Know Where the Third Shift Is?
by Ruth Toon

28 You Get What You Pay For—The Underfunded Mandate for DSPs
by John Rose

33 Breaking the Myth of Sisyphus
by Susan O'Nell
A parent's guide to understanding the DSP crisis.

38 Thoughts on Being a Professional Caregiver
by Patti Wade

40 Are You Gonna Be Here Tomorrow?
by David C. Pfriem

48 Educational Opportunities for Direct Support Professionals
by Amy Hewitt, PhD

52 "If You Build it, They Will Come"
by Marianne Taylor

56 Learning the Art of Direct Support
by Marianne Taylor

58 Loving the Ones You Love
by Robin Atwood

63 National Alliance of Direct Support Professionals Code of Ethics

66 Why Bother?
by Mike Cook
A Skeptic Shares His Thoughts on a Code of Ethics for Direct Support Staff

67 Going From Paper to Practice Teaching Ethics to DSPs
by David Chrisco

70 Exceptional Direct Support Professionals
A salute to direct support professionals who were nominated forrecognition for the exemplary care and support they provide.

79 Maybe It's Genetic...
What Kids Think of Their DSP Parents

80 Shawn and Patrick: A Self-Advocate and Direct Support Professional Partnership that Blossomed Into Friendship
by Shawn Raymer, Patrick Imel, and Judith Stevens

82 From Acquaintance to Partnership
by Mark Olson and Cliff Poetz

85 Profiles in Excellence
Compiled by the Irwin Siegel, Inc.

88 EDITORIAL COMMENTARY: The Case for Universal Newborn Screening
by Charles P. Hehmeyer
A call to action on the dire need for newborn screening nationwide

94 Waiting for Kimbi
by Patricia V. Wood
A mother's quest to help her daughter with Hallervorden Spatz syndrome led her to found an organization that promotes research into this rare disorder.

97 David's Story
by Linda Weiford
A mother writes about her family's journey with autism

101 Software for Learning: Part 3, Linking Software Evaluation to the IEP
by James W. Forgan,PhD and Roberta K. Weber, EdD and Gale Jurasek

EDITORIAL INDEX 2001

SEPTEMBER
Education

22 Models of Excellence in Education
EP salutes exceptional educators and programs that have greatly contributed to inclusion in the classroom and community.

38 Integrated Preschool Classrooms: Learning Together and From One Another
by Ronald S. Lenkowsky, EdD
A look at preschool classrooms where children with and without disabilities are learning together without labels or distinctions.

44 Educating Children with Chronic Illness
by Ann G. Bessell, PhD
A mother and researcher fights for the right to an education for children who are in the fight of their lives against illness.

50 Need-to-Know Changes in IDEA
by Sara Pankaskie, PhD, and Shelly Weiss, EdS
Answers to questions that parents may have about related services as they apply specifically to transitioning from school to the community.

56 The Universal Learning Center
by Lucinda M. O'Neill
Helping Teachers and ParentsFind Accessible Electronic Learning Materials for Students with Disabilities

60 Everything You Always Wanted to Know About Related Services
by Beth Randall
They're Baaaack! Mothers from Hell 2 pokes fun at IEPs.

62 "Practice" Makes Perfect
by Syndee Kraus, Kelly Maxwell, and R.A. McWilliam
Research Looks at Family-Centered Practices in Early Elementary Grades

64 Preparing Students with Learning Disabilities for College: Pointers for Parents, Part 1
by Andrew V. Beale, EdD, and Melissa M. Ericksen-Radtke, MEd
Suggestions to assist parents in working to include college as an option for their children with learning disabilities. Part 1 covers elementary and middle school.

70 How the Click of a Mouse Changes Lives
by United Cerebral Palsy
A record-breaking online donation to UCP ushers in the age of "e-philanthropy."

74 Infantile Spasms–A Seizure Disorder of Infancy
by Matthias C. Kurth, MD, PhD
A case study and in-depth look at this often undiagnosed disorder.

79 Editorial Commentary: Current Topics in Newborn Screening: Political Issues
by John Sorrentino
A discussion of the current climate in Newborn Screening.

86 Sometimes It Takes a Village
by Jann Moore
A look at life in Annandale village.

105 The NPA Parent and Family Advocate Special Interest Group
by Mike Hynan, PhD

110 Annual Listing of Schools, Camps, and Residences

OCTOBER
Toys

20 The Serious Business of Play
by Gale Jurasek
Introducing toys tested and reviewed by parents, therapy professionals, and kids.

26 Toy Selections From Our Toy Reviewers
Our toy experts give us their picks for new toys as well as some true classics.

30 Accessing Fun
Readers' suggestions for toys, toy adaptations, and play time activities that work for their children.

30 Toys for Fun and Learning
by Eva Briggs

32 The Toy Doctor's Prescription for Play

34 Magnets Make Toys Attractive
by Louise Kinross

36 Ideas for Kids with Visual Impairments
by Debbie Carson

38 Jami's Toys
by Manuela de Goeij

38 Hooked on Books
by Jodi Prather

40 Spooktacular Costume Ideas
EP readers let us in on their secrets for great Halloween costumes.

52 Some Bright Ideas for Play with Your Child
by Debra Siegel
Tips for helping your child get the most out of play time.

54 Holiday Activities
by Debby Entwistle and Jo Ann Hughes
Directions for making beautiful masks—for Halloween or any time you feel festive!

56 Preparing Students with Learning Disabilities for College: Pointers for Parents, Part 2
by Melissa M. Ericksen-Radtke, MEd, and Andrew V. Beale, EdD
Suggestions to assist parents in working to include college as an option for their children with learning disabilities. Part 2 focuses on the high school years.

63 Challenging Healthcare and Winning at Special Olympics' Wellness Park
by Susan Carucio Colacello
Kids with special needs can get valuable health screenings from the professionals at Special Olympics' Wellness Park.

66 Attachment and the Child With Special Needs
by Dianne I. Maroney, RN
The importance of the physical and emotional bonds between infants and parents.

75 Hunt for an Elusive Gene
by Joanne and Rob Forstall (with Jennifer Cannataro)
Parents tell the story of their daughters' rare disease (BridgeMar syndrome) and their race against time to find the gene that causes it.

NOVEMBER Technology

24 Assistive Technology: A Success Story

by Garth Heid and Jeannette Van Houten

The AT team—including parents—follows a course of action to help a student with multiple disabilities acquire and use AT in school.

28 EP Survey—Top Disability Web Sites, Part 2

Results of the EP survey we introduced in June.

30 Affordable Recreational Equipment

by Rick Escobar

A rehabilitation technologist shares some ways to make adapted scooters and tricycles.

32 Innovative Web Sites Use the Internet to Breakdown Real Barriers

A look at what is offered on WheelchairNet and AbilityForum.com.

34 My Dog Ate My PDA

by Anne M. Bauer, EdD, and Mary E. Ulrich, EdD

A study of the use of personal digital assistants (PDAs), a new generation of handheld computers, in an inclusive classroom.

38 Popping the Clutch

by Kate Thomsen

A parent of a child with a learning disability talks about knowing when to help with schoolwork and when to let go.

44 Darwin's Nose Job

by Susanne Carter

A Story of Maternal Anxiety and Advocacy

By working as a team, parents and hospital staff can make the going easier for children with disabilities.

50 Coping With Disaster

by Anne Farrell, PhD, and Daniel Crimmins, PhD

A Guide for Supporting Children With Cognitive Disabilities

How to help your child weather traumatic times.

60 It All Begins in the Home

by Joseph M. Valenzano, Jr.

EP's publisher takes some time with author and advocate Maria Shriver about the importance of teaching children the right lessons.

66 Living with Prader-Willi: The "Starving Syndrome"

by Linda A. Thomas and Merlin G. Butler, MD, PhD, FACMG

DECEMBER Family, Friends & the Community

20 Siblings Speak Out

A group of young people get together and express their feelings about having a sibling with a disability.

22 A 21st Century Mission

by Lucinda M. O'Neill

The first CAST Institute on Universal Design for Learning helps educators learn how better to implement technology and the use of digital text in their classrooms.

26 Living with MPS: Mitch's Story

Members of the Moore family discuss their experience with Hunter syndrome.

30 Interview with Governor Jeb Bush

by Joseph M. Valenzano, Jr.

EP Publisher Joseph M. Valenzano, interviews Florida Governor Jeb Bush about his administration's efforts to help families and individuals who are living with disabilities.

34 Luz' Story: The Power of Family Love

by Luz Elena Aponte

The story of how the Aponte family got involved and made things happen.

38 Coping With Disaster

by Anne Farrell, PhD, and Daniel Crimmins, PhD, with Suzanne Bushby, MA, Monica Feinberg, PhD, and Dana Leonardi, PhDEPA

Guide for Parents and Other Caregivers

48 Hereditary Colon Cancer

by Beth Schreiber

A closer look at hereditary colon cancer and the effect on individuals and families dealing with the disorders.

52 WCD Roundup

A review in pictures of the 2001 World Congress & Exposition on Disabilities in Atlanta, GA.

62 Remembering Malki

A mother and a father write about Malka Chana Roth, their daughter who was murdered.

85 In Memoriam

Dr. Stanley Herr, a beloved advocate for individuals with disabilities, dies.

EDITORIAL INDEX 2001

DEPARTMENTS

Ask The Doctor

Attention Deficit Disorder: After the Diagnosis; Dana Rubin, MD, MSW; Feb. 44

Wilson's Disease; H. Ascher Sellner, MD; Mar. 34

Diagnosing and Treating Osteoporosis Among Adults with Disabilities; Jon J. Michnovicz, MD, PhD; Apr. 44

Don't Let the Well Run Dry: The Importance of Water to Your Child's Health; Marybetts Sinclair, LMT, and Anna Von Weller, RD, LD; May 66

Your Finicky Eater: A Guide for Parents; Meeta R. Patel, PhD, and Cathleen C. Piazza, PhD; Jun. 82

Meet the Professional: Child Life Specialists: Making the Tough Times a Little Easier; Cinda McDonald, RDH, CCLS; Jul. 80

Constipation and Fecal Incontinence; Chris Feudtner, MD, PhD, MPH; Sep. 107

Swallowing Safety; Justine Joan Sheppard, PhD; Oct. 68

Prader-Willi Syndrome; Merlin G. Butler, MD, PhD, FACMG; Nov. 78

Focus on Pediatric Movement Disorders: Ataxia; Terence Sanger, MD, PhD, with Joy E. Bartnett, AMIA, AMWA, NASW; Dec. 68

Book Notes

When Your Child Has a Disability; Mar. 22

Asperger's Syndrome—A Guide for Parents and Professionals; Apr. 83

Everybody Belongs—Changing Negative Attitudes Toward Classmates with Disabilities; May 78

The Parent's Guide to Food Allergies; May 78

Making a Place for Kids with Disabilities; May 78

The New Social Story Book: Illustrated Edition; Jun. 88

Ask a Nurse: From Home Remedies to Hospital Care; Jun. 88

We Can Do It!; Jun. 89

Easy for You to Say; Jul. 73

Raising Children Who Refuse to Be Raised; Jul. 73

One Step at a Time; Jul. 72

Kids with Celiac Disease: A Family Guide to Raising Happy, Healthy, Gluten-Free Children; Aug. 118

How To Be a Para Pro: A Comprehensive Training Manual for Papaprofessionals; Aug. 118

Taking Cystic Fibrosis to School; Sep. 104

Taking Cerebral Palsy to School; Sep. 104

Trick-or-Treat for Diabetes; Sep. 104

Everything You Need to Know About Behavior Management: An Early Childhood Curriculum for Typically Developing Children and Children with Special Needs; Oct. 51

What's Wrong With Timmy?; Nov. 59

Children's Page

Glad About My Brother; Jeremy Goulet; Feb. 100

Looking "Up" to My Little Sister; Lauren Sakin; Mar. 108

Fighting Prejudice; Abigail Seaver; Apr. 116

What Is Different?; Sara Poole; May 108

Iron Will; Beth Stepanczuk; Jun. 108

The Real Joe; Joe Bishop; Jul. 108

My Friend, the Butterfly; Erin Grimm; Aug. 140

Heroes; Noa Elimelech; Sep. 148

My Cousin, Austin; Kayla Quinn; Oct. 108

I Am; Liz Unger; Nov. 100

My Sister; Jessica Ebersole; Dec. 92

Corporations that Care

May 74

Dial Independence: Innovative programs at Verizon help people with disabilities-of all ages-communicate independently.

Editor's Desk

Feb. 10, Mar. 12, Apr. 10, May 10, Jun. 8, Jul. 10, Aug. 10, Sep. 10, Oct. 8, Nov. 10, Dec. 8

Familiar Faces

Feb. 70, Mar. 72, Apr. 92, May 93, Jun. 14, Jul. 86, Aug. 115, Sep. 95, Oct. 55, Nov. 62, Dec. 60

Legislative Update

Feb. 85, Apr. 70, May 96, Jun. 77, Jul. 70, Aug. 60, Dec. 84

Letters to the Editor

Apr. 15, Jul. 12, Nov. 20

Medical Research Update

Feb. 77, Apr. 88, Mar. 94, Jul. 93

Organizational Spotlight

The Colleen Giblin Foundation for Children's Neurological & Cancer-Related Research; Feb. 86

The Child Neurology Society; Mar. 68

Families of Spinal Muscular Atrophy (SMA); Apr. 84

Pediatric Neurotransmitter Disease Association; May 85

The Rett Syndrome Research Foundation; Jun. 93

Brave Kids; Jul. 76

The National Alliance for Direct Support Professionals; Aug. 61

The Sturge-Weber Foundation; Sep. 91

The National MPS Society, Inc.; Oct. 72

Prader-Willi Syndrome Association (USA); Nov. 74

Hereditary Colon Cancer Association; Dec. 45

Parent Perspective

Balancing Optimism with Realism for Children with Special Needs; Jeffrey E. Horvitz; Sep. 88

The Gazebo; Nina Simon; Oct. 62

Trust in God and Unconditional Love; Carrie Polete; Nov. 64

Attitude is Everything; Susan Elizabeth Nus, Dec. 65

Role Model

Role Model: Jo Waldron: Breaking the Sound Barrier; Mar. 62
by Grace M. Sciré

Role Model: Growing Up with a Disability; Apr. 74
by Melissa Crisp

What's Happening

Newsletter for Parents of Children Who Stutter; Drug Interactions Guide; Video on Dental Care for Individuals with Cerebral Palsy: Feb. 80

Web Site for Weather Forecasts; Youth Baseball a "Hit" with the Pros; IDEA Web Site: Mar. 20-21

New IRS Tax Deductions; The Great Mississippi River Race; Speech-to-Speech Phone Assistance Now Available Nationwide: Apr. 80-81

Cleft Palate Foundation Web Site Now Available in Spanish; New National Campaign Launched to Educate on Children's Mental Health; Robert Wood Johnson Foundation's Faith in Action Grant; New Video, Booklet on ADA in Public Schools: May 77

Free Narrated Recordings of Articles Available Online; Free Guide Gives Tips on Getting Funding for Standing Technology: Jun. 89

Seeking Nominations for the Epilepsy Foundation's Accomplished Woman Award; Guide for People With Disabilities Seeking Employment: Jul. 71

The Serena Merck Memorial Award for Innovation and Dedication in Practice; Longest Canoe/Kayak Race in History for Rett Syndrome Research: Aug. 116

Free Online Courses; Assistive Technology Awards for Students: Sep. 102

Tips for a Safe Halloween; Disability-Related Publications Available: Oct. 44

US Fund for UNICEF Accepts/Delivers Letters, Cards, and Drawings for Children Affected by the September 11 Tragedy; Free Assistive Technology Brochures: Nov. 57

SPECIAL REPORTS

Contemporary Issues in Epilepsy

Contemporary Issues in Epilepsy, Part. 2; Feb. 88, **Part. 3;** Mar. 83

The EP Guide to Every Body

Part 1; Apr. 24
by Jane Braverman, PhD
Respiratory Compromise and the Child with Special Healthcare Needs

Part 2; May 60
by Jane Braverman, PhD
Respiratory Compromise and the Child with Special Healthcare Needs: Impaired Airway Clearance

Part 3; Jun. 56
by Jane Braverman, PhD
Respiratory problems in individuals with Cerebral Palsy: Recognition, Management, and Prevention

Part 4; Aug. 126
by Jane Braverman, PhD
Maintaining Healthy Lungs: The Role of Airway Clearance Therapy

Part 5; Sep. 118
by Jane Braverman, PhD
Respiratory Compromise: A Barrier to Recovery After Spinal Cord Injury

Part 6–Spinal Muscular Atrophy: Strategies for Living; Oct. 94
by Jane Braverman, PhD

Part 7–Cystic Fibrosis: No Longer a Fatal Disease; Nov. 87
by Jane Braverman, PhD

Part 8; Dec. 79
by Jane Braverman, PhD
Meeting the Challenges: Pulmonary Complications in Duchenne Muscular Dystrophy

Oral Healthcare for People with Special Needs

Something to Smile About: Oral Healthcare for People with Special Needs, Part I; May 69
by Stephen Perlman, DDS, MScD, Stanford J. Fenton, DDS, MDS, and Clive Friedman, DDS, Cert. Pediatric Dentist
The first in a series of twelve articles on this integral component of overall health.

Forewarned Is Forearmed—Oral Healthcare for People with Special Needs, Part II; Jun. 79
by Stephen Perlman, DDS, MScD, Stanford J. Fenton, DDS, MDS, and Clive Friedman, DDS, Cert. Pediatric Dentist
Preventative measures and early warning signs of potential dental problems.

Nutrition and Diet Health in "Exceptional" Children—Oral Healthcare for People with Special Needs, Part III; Jul. 66
by Riva Touger-Decker, PhD, RD, FADA
A healthy diet and plenty of exercise are vital components in achieving optimum oral and overall health.

Caregivers and Healthcare Providers as "Dental Detectives" Oral Healthcare for People With Special Needs, Part IV; Aug. 113
by Robert Ealy Jr., DDS

Oral Healthcare for People with Special Needs, Part V–the ABCs for Successful Dental Treatment; Sep. 133
by Sandford J. Katon, MDS, and Carlton V. Horbelt, DDS
How the dental team can ease a visit to the dentist's office.

Oral Healthcare for People with Special Needs, Part VI–Finding Your Car in the Parking Lot; Oct. 89
by David A. Tesini, DMD, MS

Oral Healthcare for People with Special Needs, Part VII–The Role of Protective Support: Appropriate Use of Restraint in the Dental Treatment of People with Special Needs; Nov. 80
by Charlotte Connick, RDH, MS, and Clive Friedman, DDS

Oral Healthcare for People with Special Needs, Part VIII; Dec. 72
by Carlos F. Salinas, DMD
The Relationship between Genetic Disorders and Oral Health, Part I

Options in Seizure Managment

Options in Seizure Management: The Vagus Nerve Stimulator—Experiences to Date

Part 1: An Introduction to Seizure Disorders and Existing Therapies; Aug. 107

Part 2: Addressing Challenges to VNS Use and Quality of Life Issues; Sep. 136

Part 3: Long-Term Results and New Directions; Oct. 81

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.
Scooters and chairs that won't fit in other vans can fit in a Kneelvan.
KneelVan
Kneelvan is the most reliable lowered floor minivan ever.
More ground clearance than any other lowered floor minivan.
Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel**. Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."
On the web at: www.freedommotors.com

Circle #61 or visit www.eparent.com/adinfo

CANADIAN RESOURCES

This directory contains organizations dedicated to helping people dealing with disabilities throughout Canada. It is divided by province into the following categories: Community Living; Early Intervention; Education; Employment; Life Planning; Literacy; Outreach and Support; Specific Disabilities (see "National Specific Disabilities" starting on page 22 for more listings, including Canadian-based organizations); and Travel. We have categorized organizations according to the descriptions they provided on their surveys; however, some organizations provide many services that fall into more than one category. Other organizations provide services only for individuals with specific disabilities and their families, or to those who meet certain other criteria. We urge readers to contact organizations directly for more information.

USING THIS DIRECTORY

When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the symbol ✉. Web sites are listed with the standard **http://** before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

COMMUNITY LIVING

ALBERTA

Alberta Association for Community Living
11724 Kinsgway Ave.
Edmonton, AB
Canada T5G 0X5
(780) 451-3055
(780) 453-5779 (fax)
✉mail@aacl.org

Alta Life Care Housing Foundation
4069-106 St.
Edmonton, AB
Canada T6J 2S3
(780) 437-7171
(780) 437-5551 (fax)
✉liferes@edmc.net

Between Friends Club for Youth with Disabilities
304-501 18th Ave. SW
Calgary, AB
Canada T2S 0C7
(403) 508-0114
(403) 269-3919 (fax)
✉fundcomm@betweenfriends.ab.ca

Calgary Community Living Society
#202, 501-18 Ave. SW
Calgary, AB
Canada T2S 0C7
(403) 245-4666
(403) 228-2132 (fax)
✉ccls@cadvision.com
http://www.cadvision.com/ccls

Community Enrichment Grant MacEwan College
PO Box 1796, 7-194
Edmonton, AB
Canada T5J 2P2
(780) 497- 5117
(780) 497-5116 (fax)

Gateway Assn. For Community Living 11728 Kingsway Ave. NW
Edmonton, AB
Canada T5G 0X5
(780) 454-0701
(780) 454-0843 (fax)
✉gacl@compusmart.ab.ca
http://www.compusmart,AB,CA.GACl

Leduc Community Living Association
5007-47 St.
Leduc, AB
CanadaT9E 7HR
(780) 986-4193
(780) 986-4230 (fax)

Lethbridge Association For Community Living
207, 542-7 St. South
Lethbridge, AB
CanadaT7J 2H1
(403) 327-2911
(403) 320-7054 (fax)
✉lacl40@telusplanet.net

Southern Alberta Community Living Association
401-21 A St. North
Lethbridge, AB
Canada T1H 6L6
(403) 329-1525
(403) 329-1435 (fax)
http://www.sacla.ab.za

Southern Alberta Society for the Handicapped
22 N. 1st St. W.
Magrath, AB
Canada TOK 1J0
(403) 758-3334
(403) 758-3644 (fax)
✉rfromm@telusplanet.net

Wainwright Association for Community Living
205 10th St.
Wainwright, AB
Canada P9W 1N7
(780) 842-2666
(780) 842-5908 (fax)
✉wack@telusplanet.net

BRITISH COLUMBIA

BC Association for Community Living
300-30 E. 6th Ave.
Vancouver, BC
Canada V5T 4P4
(604) 875-1119
(604) 875-6744 (fax)
✉info@bcacl.org
http://www.bcacl.org

Burnaby Association for the Mentally Handicapped
2702 Norland Ave.
Burnaby, BC
Canada V5B 3A6
(604) 299-7851
(604) 299-5921 (fax)
✉jstyan@direct.ca

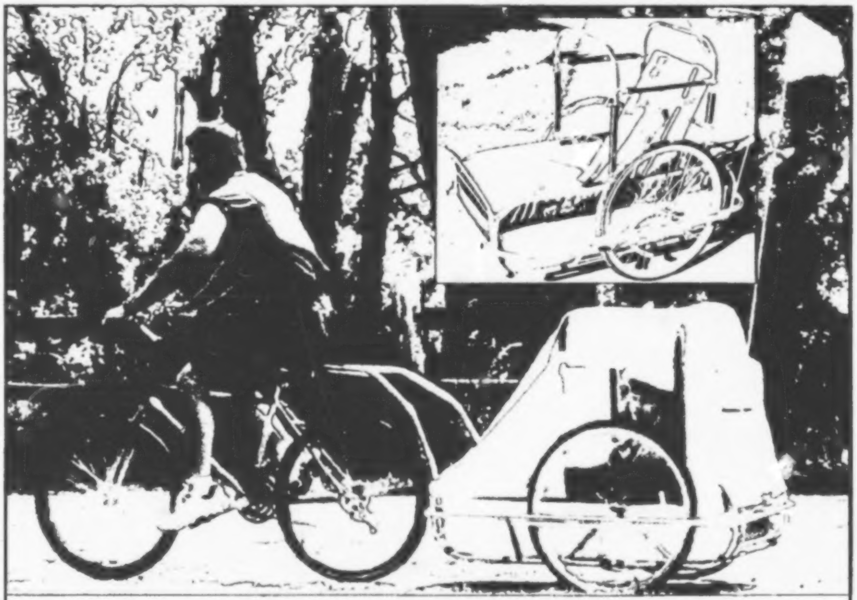
Cheshire Homes Society of British Columbia
203, 5066 Kingsway
Burnaby, BC
Canada V5H 2E7
(604) 451-0686
(604) 451-0680
✉cheshire@intergate.ca

Comox Valley White Cane Club
1446 Dogwood Ave.
Comox, BC
Canada V9M 2Z5
(250) 339-3632
✉patm@marsark.com

Cranbrook Society for Community Living
201, 22-14th Ave. S.
Cranbrook, BC
Canada V1C 2W8
(250) 426-7588
(250) 426-7990 (fax)
✉cscl@cintek.com

Developmental Disabilities Assn.
#100-3851 Shell Rd.
Richmond, BC
Canada V6X 2W2
(604) 233-5400
(604) 273-9770 (fax)
✉ldyson@develop.bc.ca

Elk Valley Society for Community Living
Box 1139
Fernie, BC
Canada V0B 1M0
(250) 423-7635
✉pelletier@elkvalley.net



Enjoy the out-of-doors together with a

CycleTote® Bicycle Trailer
Running Stroller

1-800-747-2407 www.cycletote.com

Satisfaction Guarantee/Lifetime Warranty

HDIS

Convenient Home Delivery of Bladder Control Products

Get a FREE bladder control products catalog from the caring professionals at HDIS.

At HDIS, we've been providing discreet home delivery of bladder control products for more than 15 years.

Our friendly, knowledgeable Customer Care Representatives will help you choose which products are right for your child, and answer any of your questions. ***Name brands always in stock—Depend®, Attends®, Reassure®, Tranquility® and more!***

FREE CATALOG!

Call 1-800-2MY-HOME®

(1-800-269-4663)

"If you have any questions, give us a call. We're happy to help."
– Mary

Call now to get your FREE 40-page HDIS catalog of bladder control products and over $45 in coupons—all sent to you in a discreet envelope.

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

Copyright 2002, HDIS 024-125

Circle #67 or visit www.eparent.com/adinfo

The Many Faces of Matheny.

A lifetime of caring for people with developmental disabilities.

Award-winning programs for children and adults in medicine, dentistry, therapy, and education

- Residential
- Outpatient
- Respite

As an affiliate of major universities and hospitals, Matheny shares its expertise with the medical community.

MATHENY
School and Hospital
Main Street, P.O. Box 339
Peapack, NJ 07977
908.234.0011
www.matheny.org

Circle #88 or visit www.eparent.com/adinfo

Kamloops Society For Community Living
Gail Sanderes
449 St Paul Street
Kamloops, BC
V28 6B1 Canada
(250) 374-3245
(250) 374-2133 (FAX)
✉ksci@direct.ca

Langley Association for Community Living
23535-44th Ave
Langley, BC
Canada V2Z 2V2
(604) 534-8611
(604) 534-4763 (fax)
✉dcollins@langleyacl.org

Maple Ridge-Pitt Meadows Community Services Council
11907-228th St.
Maple Ridge, BC
Canada V2X 8G8
(604) 467-6911
(604) 463-2988 (fax)
✉Hvanhorne@mrpmcsc.bc.ca
✉fcugner@mrpmcsc.bc.ca

MSA Society for Community Living
30578 Old Yale Rd.
Abbotsford, BC
Canada V2T 6P7
(604) 856-7784
(604) 856-7130 (fax)

The Powell River Association for Community Living
#201-4675 Marine Ave.
Powell River, BC
Canada V8A 2L2
(604) 485-6411
(604) 485-6419

Quesnel Community Living Association
611 Anderson Dr.
Quesnel, BC
Canada V2J 3K6
(250) 992-7774
(250) 992-6651 (fax)
✉qcla@goldcity.net

Richmond Society for Community Living
180 7000 Minoru Blvd.
Richmond, BC
Canada V6Y 2T9
(604) 279-7040
(604) 279-7048 (fax)
✉rscl@istar.ca

South Peace Child Development Society
9001-10 St.
Dawson Creek, BC
Canada V1G 4T1
(250) 782-1161
(250) 782-4487 (fax)
✉sp-cdc@pris.bc.ca

MANITOBA

Association For Community Living-Winnipeg Inc
Janet Forbes Ex. Dir
980 Palmerston Ave
Winnipeg, MAN R3G 1J9
Canada
(204) 786-1414
(204) 774-4402 (fax)
aclwpy@escape.ca

Manitoba Family Services and Housing Children's Special Services
Brenda Hoover Program Specialist
2116-114 Garry Street
Winnpeg, MAN RC3 4V6
Canada
(204) 945-1279
(204) 948-4656 (FAX)
✉bhoover@fs.gov.mb.ca

L'Arche Winnipeg, Inc.
2nd Fl., 109 Bond St.
Winnipeg, MAN
Canada R2C 2L1
(204) 237-0300
(204) 237 0316 (fax)
✉llarchwpg@pangea.ca

Pulford Community Living Services, Inc.
Rod Retelback Executive Director
283 Bannatyne Ave.,
Ste. 300
Winnipeg, MAN
Canada R3B 3B2
(204) 284-2255
(204) 453-5657 (fax)
✉pulford@escape.ca
http://www.wpgebiz.com/social-services/pulford

Rolling Dale Enterprises, Inc.
533-2nd Ave.
Rivers, MAN
Canada R0K 1X0
(204) 328-7186
(204) 328-7047 (fax)
✉rdale@mb.sympatico.ca

Versatech Industries, Inc.
436 Willian Ave.
Winnipeg, MAN
Canada R3A 0J4
(204) 956-9700
(204) 943-1893 (fax)
✉vii@mb.aibn.com

W.A.S.O, Inc. (Work and Social Opportunities)
590 Washington Ave.
Winnipeg, MAN
Canada R2K 1M2
(204) 669-6688
(204) 668-0084 (fax)
✉wasoceo@mts.net

NEW BRUNSWICK

Family and Community Services
360 Pleasant St.
Miramichi, NB
Canada E1V 2N3
(506) 627-4044
(506) 622-8802 (fax)

Grand Falls Association for Community Living, Inc.
475 Terrace St.
Grand Falls, NB
Canada E3Z 1B3
(506) 475-4060
(506) 473-5998 (fax)
✉aicgs@nb.sympatico.ca

Greater Moncton Association for Community Living
PO Box 1715
Moncton, NB
Canada E1C 9X5
(506) 857-8899
(506) 858-7883

RESOURCES

NEWFOUNDLAND

Southwest Coast Association for Community Living
PO Box 488
Port Aux Basques, NF
Canada A0M 1C0

Southwest Coast Association for Community Living
P.O. Box 488
Port aux Basques, NF
Canada A0M 1C0

"Your Strength Is Our Strength" Club, Inc.
13 Abbott St.
Peterview, NF
Canada A0H 1Y0
(709) 257-3018/2884
(709) 257-3018 (fax)

NOVA SCOTIA

Halifax Regional Municipality Transit Services
Access-A-Bus
200 Ilsley Ave.
Dartmouth, NS
Canada B3B 1V1
(902) 490-6614
(902) 490-6688 (fax)
✉metroinfo@region.halifax.ns.ca

Metro Resource Centre for Independent Living
2786 Agricola St.,
Ste. 212
Halifax, NS
Canada B3E 4E1
(902) 453-0004
(902) 455-5287 (fax)
✉mrcil@dbis.ns.ca
http://www.dbis.ns.ca/~mrci/

South Shore Community Service
#5 Collicutt Rd.
Chester, NS
Canada B0T 1J0
(902) 275-5622
(902) 275-2567 (fax)

ONTARIO

Ability Online
1120 Finch Ave. W.,
Ste. 503
Toronto, ON
Canada M3J 3H7
(416) 650-6207
(416) 650-5073 (fax)
✉michelle.mcclure@ablelink.org
http://www.abilityonline.org

Access Better Living Inc.
Vie Independente et Enrichie
733 Ross Ave. E. Ste. #3
Timmins, ON
Canada P4N 8S8
(705) 268-2284 (fax)
✉ablkelly@ntl.sympatico.ca

Active Living Alliance for Canadians with a Disability
720 Belfast Rd., Ste. 104
Ottawa, ON
Canada K1G 0Z5
(613) 244-0052
(613) 244-4857 (fax)
✉wendy@ala.ca

Centre for Independent Living in Toronto (CILT), Inc.
205 Richmond St. W.
Ste. 605
Toronto, ON
Canada M5V 1V3
(416) 599-2458
(416) 599-3555 (fax)
✉cilt@cilt.cnd.com
http://www.cilt.ca

Chatham & District Association for Community Living
PO Box 967, 240 Grand Ave. W., Ste. 212
Chatham, ON
Canada N7M 5L3
(519) 352-1175
(519) 352-5459 (fax)

Family Support and Resource Network of Chatham-Kent
143 Wellington St W.
Suite 104
Chatham, ON N7M 5K4
Canada
(519) 352-7827
✉ckasfsrn@netrover.com
http://netrover.com/~ckas-fsrn

Community Living -South Huron
144 Main St.
PO Box 29
Dashwood, ON
Canada N0M 1N0
(519) 237-3637
(519) 237-3190 (fax)
✉clsh@hay.net

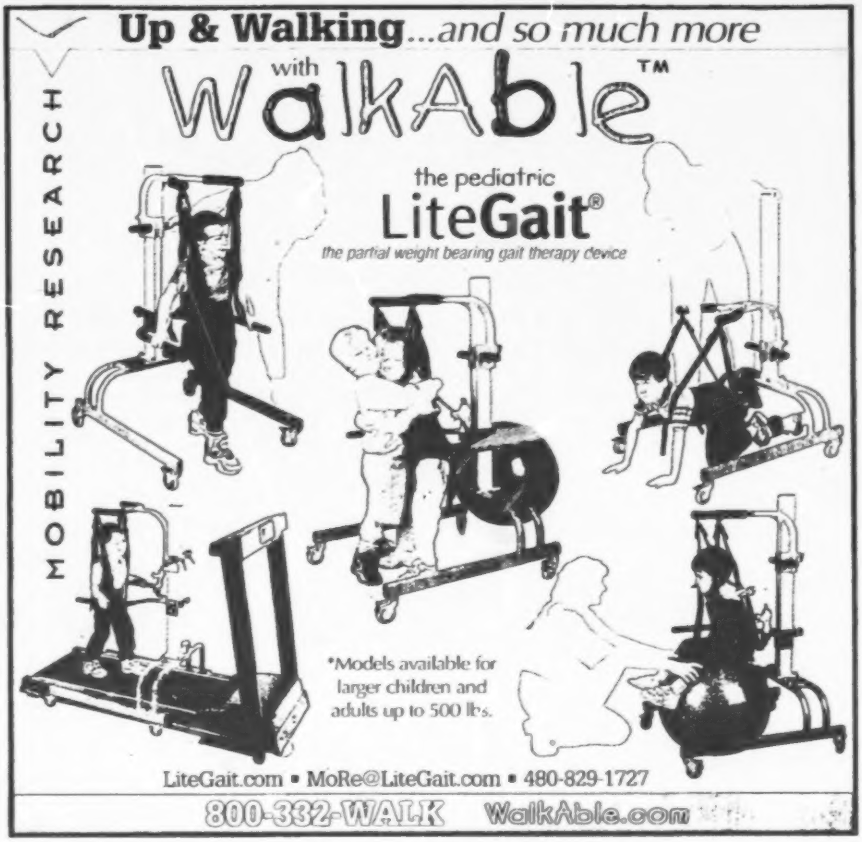
Community Living -South Muskoka
23-3 Ball's Dr.
Bracebridge, ON
Canada P1L 1T1
(705) 645-5494
(705) 645-4621 (fax)
✉clsmcthink@iprimus.com

Extend-A-Family
200-3300 Yonge St.
Toronto, ON
Canada M4N 2L6
(416) 484-1317
(416) 484-1589 (fax)
✉eaf@idirect.com

The Friends
27 Forest St.
Parry Sound, ON
Canada P2A 2R2
(705) 746-5012
(705) 746-8139 (fax)
✉friends@vianet.on.ca

Guelph-Wellington Barrier Free Committees
59 Carden St.
Guelph, ON
Canada N1H 3A1
(519) 837-5625
(519) 826-9771 (TDD)
(519) 837-5648 (fax)
✉specialneeds@city.guelph.on.ca

Haliburton County Association for Community Living
PO Box 90
Haliburton, ON
Canada K0M 1S0
(705) 457-1135
(705) 457-9287 (fax)
✉hcacl@sympatico.ca


Up & Walking...and so much more
with WalkAble™
MOBILITY RESEARCH
the pediatric LiteGait®
the partial weight bearing gait therapy device
*Models available for larger children and adults up to 500 lbs.
LiteGait.com • MoRe@LiteGait.com • 480-829-1727
800-332-WALK WalkAble.com

Circle #93 or visit www.eparent.com/adinfo

Mulholland
Positioning Systems Inc.
215 North 12th Street
PO Box 391
Santa Paula
93061
Tel # 800-543-4769
Fax # 805-933-1082

The Exciting Meywalks:

- Weight-relieving adaptive-ambulator which loads from the rear and has a powerful lever to lift the seat to a standing position.
- Height adjustable
- Many accessories available
- Capacities from 25 to 220 lbs

www.mulhollandinc.com customer_service@mulhollandinc.com

Circle #95 or visit www.eparent.com/adinfo

CANADIAN RESOURCES

Hintonburg Community Centre
1064 Wellington St. W.
Ottawa, ON
Canada K1Y 2Y3
(613) 798-8684
(613) 798-8877 (fax)
✉dondalel@city.ottawa.on.ca

Homes of Learning Development
96 Sherwood Dr
Brantford, ON
Canada N3T 1N7
(519) 753-5529
(519) 753-5529 (fax)
✉Brinleigh@home.com

The Independent Living Centre - London & Area
433 King St., Ste. 101
London, ON
Canada N6B 3P3
(519) 660-4667
(519) 660-6818 (fax)
✉pquesnel@odyssey.on.ca

Kids' Connection
Don Murphy
1201 Jasper Drive Suite A
Thunder Bay, ON
Canada P7B 6R2
(807) 343-0414
(807) 344-6140 (fax)
✉allan-buchan@hotmail.com

Lions Foundation of Canada; Special Skills Dogs of Canada; Canine Vision Canada; Hearing Ear Dogs of Canada
152 Wilson St.
PO Box 907
Oakville, ON
Canada L6J 5E8
(905) 842-2891
(905) 842-3373 (fax)
✉lbridgef@dogguides.com
✉info@dogguides.com

Northern College Community Living Skills
140 Government Rd. E.
Kirkland Lake, ON
Canada P2N 3L8
(705) 567-9291 ext.681
(705) 568-8186 (fax)

On The Move Community Integration Association
15 Manor Rd. E.
Toronto, ON
Canada M4S 1PG
✉suzirf@sympatico.ca
http://www.onthemove.ca

Ottawa Valley Autistic Homes (OVAH)
235 Donald St., Ste. 200
Ottawa, ON
Canada K1K 1N1
(613) 746-2722
(613) 746-277 (fax)
✉pvgmdir@ovah.on.ca

Participation House Project-Waterloo Region
151 Frederick St., Ste. 200
Kitrchener, ON
Canada N2H 2M2
(519) 741-5845
(519) 741-8731 (fax)
✉deb@phwaterloo.com

Participation House Support Services London and Area
Cornell Tait
633 Colborne Street
London, ON N6B 2V3
Canada
(519) 660-6635 ext 223
(519) 660-1654 (fax)
info@particionhouse.com

Participation Lodge Grey/Bruce
RR #1
Holland Centre, ON
Canada N0H 1R0
(519) 794-3201
(519) 794-4186 (fax)
✉partlodge@bmts.com

SMARTRISK
790 Bay St.
Toronto ON
Canada MS6 1N8
(416) 977-7350
(416) 596-2700 (fax)
✉Kblair@smartrisk.ca

Therapeutic & Educational Living Centres Inc.
25 Tower Rd.
Ottawa, ON
Canada K2G 2E4
(613) 226-6237
(613) 226-6950 (fax)
✉telci@cyberus.ca

Windsor Community Living
7025 Enterprise Way
Windsor, ON
Canada N8T 3N6
(519) 974-4221
(519) 974-4157 (fax)
✉wclss@mnsi.net

PRINCE EDWARD ISLAND

Queens County Residential Services, Inc. (QCRS Inc.)
94 Mt. Edward Rd.
Charlottetown, PE
Canada C1A 5S6
(902) 629-4426
(902) 566-9998 (fax)
✉qcrs@pei.sympatico.ca

QUEBEC

Mackay Center
3500 Decarie Blvd.
Montreal, QC
Canada H4A 3J5
(514) 482-0500
(514) 482-4536 (fax)

Multi-ethnic Association for the Integration of Persons with Disabilities
6462, St. Laurent Blvd.
Montreal, QC
Canada H2S 3C4
(514) 272-0680
(514) 272-8530 (fax)
✉ameiphq@total.net

SASKATCHEWAN

Neil Squire Foundation
#100-2445 13th Ave.
Regina, SK
Canada S4P 0W1
(306) 781-6023
(306) 522-9474 (fax)
✉sk.info@neilsquire.ca

Saskatoon Association for Community Living, Inc.
102-135 Robin Crescent
Saskatoon, SK
Canada S7L 6M3
(306) 652-9111
(306) 652-9112 (fax)
✉sack@sk.sympatico.ca

EARLY INTERVENTION

BRITISH COLUMBIA

Buckley Valley Child Development Centre
Box 995
3350 Poplar Rd.
Smithers, BC
Canada V0J 2N0
(250) 847-4122
(250) 847-9338 (fax)
✉bvcdc@uniserve.com

Step by Step Child Development Society
200-2232 McAllister Ave.
Port Coquitlam, BC
Canada V3C 2A6
(604) 552-0896
✉stepbystep@telus.net

Terrace Child Development Centre Society
2510 S. Eby St.
Terrace, BC
Canada V8G 2X3
(250) 635-9388
(250) 638-0213 (fax)
✉tcdc@osg.net

Infant Development Programs of BC
2765 Osoyoos Crescent
Vancouver, BC
Canada V6T 1X7
(604) 822-4014
(604) 822-9556 (fax)
✉infantdv@interchange.ubc.ca

Comox Valley Child Development Association
#1-635 Fitzgerald Ave.
Courtenay, BC
Canada V9N 2R4
(250) 338-4288
(250) 338-9326 (fax)
✉osa@island.net

Cariboo Chilcotin Child Development Centre
690 North Second Ave.
Williams Lake, BC
Canada V2G 4C4
(250) 392-4481
(250) 392-4432 (fax)

NEW BRUNSWICK

Early Childhood Stimulation, Inc.
Stimulation a l'enfance, Inc.
118 Halifax St.
Moncton, NB
Canada E1C 9S1
(506) 853-0575
(506) 857-3990 (fax)
✉louise@ecsae.nb.ca

southpaw enterprises®
DAYTON, OHIO U.S.A.

Providing Hundreds of Sensory Integration and Development Product Solutions!

Therapists, educators, parents and physicians acknowledge Southpaw as the industry leader in providing high-quality, state-of-the-art and safe Sensory Integration and Developmental products. Our products are made to the strictest standards of quality. We also strive to make our products fun while providing you with the innovative and safe solutions you require for great therapy.

Phone toll free:
1-800-228-1698

Or contact us from our website:
www.southpawenterprises.com

Call for our FREE full line product catalog!

Southpaw Enterprises
P.O. Box 1047
Dayton, OH 45401-1047

Circle #119 or visit www.eparent.com/adinfo

Moncton Headstart Inc.
1111 Mountain Rd.
Moncton, NB
Canada E1C 2S9
(506) 858-3170 (fax)
(506) 858-8252
✉headstrt@nb.sympatico.ca

South East Rural Early Intervention Program
PO Box 24051
Riverview, NB
Canada E1B 4T6
(506) 386-4304
(506) 386-4305 (fax)

Sussex and Area Early Intervention
717 Main St., Unit 2
Sussex, NB
Canada E4E 7H7
(560) 432-4590
(560) 432-4591 (fax)
✉saeii@nbnet.nb.ca

NOVA SCOTIA

Queens Early Childhood Development Association
79 School St.
PO Box 1689
Liverpool, NS
Canada B0T 1K0
(902) 354-5890
(902) 354-5004 (fax)
✉qecda@ns.sympatico.ca

Progress Center For Early Inelervention
Patricia Morse
South Tower 12 On Tower Road
Suite 104
Halifax, NS Canda B3H 4K6
(902) 423-2686
(902) 425-3360 (fax)

Valley Child Development Association
PO Box 63
Kentville, NS
Canada B4N 3V9
(902) 678-6111
(902) 678-6112 (fax)
✉vcda@ns.sympatico.com

ONTARIO

City of Windsor Social Services Dept.
Children's Services Division
500 Ouellette Ave.
Windsor, ON
Canada N9A 1B3
(579) 255-5377
(579) 255-7619 (fax)

George Jeffrey Children's Treatment Centre
507 N. Lillie St.
Thunder Bay, ON
Canada P7C 4Y8
(807) 623-4381
(807) 623-6626 (fax)
http://www.gjctc.on.ca

SASKATCHEWAN

SCEP CENTRE Early Intervention and Training Services
3105 4th Ave. N.
Regina, SK
Canada S4R 0V2
(306) 543-6944
(306) 545-0199 (fax)
✉scepcentr@asksympatico.ca

YUKON

Child Development Centre
Box 2703
Whitehorse, YT
Canada Y1A 4P7
(867) 667-8182
(867) 393-6374 (fax)
✉cdc.whitehorse@yt.sympatico.ca

EDUCATION

ALBERTA

Alberta Learning Materials Resource Center
Kathrlyn Ribeiro
12360 142 St NW
Edmonton, AB
Canada T5L 4X9
(780) 427-5212
(780) 427-6638 (FAX)
✉kathrynribeiro@gov.ab.ca

NorQuest College
10215-108 St.
Edmonton, AB
Canada T5J 1L6
(780) 427-5467
(780) 415-8882 (fax)
✉suzanne [illegible]anteluk@norquest.ab.ca

BRITISH COLUMBIA

Sal'i'shan Institute Society
PO Box 242
Chilliwack, BC
Canada V2P 6J1
(604) 792-7300
(604) 792-5498 (fax)
✉salishan@dowco.com

MANITOBA

Manitoba School for the Deaf
242 Stradford St.
Winnipeg, MB
Canada R2Y-2C9
(204) 945-8934
204) 945-1767 (fax)

NEW BRUNSWICK

Neil Squire Foundation
May Burrell
Suite 104 440 Wilsey Rd
Fredericton, NB
Canada E3B 7G5
(506) 450-7999
(506) 453-9681 (FAX)
✉nbinfo@neilsquire.ca

Visit Our Community...

Beverly Farm Foundation

Visit our web site: www.beverlyfarm.org

Serving adults with developmental disabilities age 18 and older, we offer several choices of residential living set on 220 scenic acres in Godfrey, Illinois:

◆ Group homes for intermediate functioning individuals
◆ Apartment living for higher functioning individuals
◆ On-campus cottages for severe/profound individuals

Programs and services include:

◆ *Nationally Accredited Training Center*
◆ *Horticultural Therapy*
◆ *Aquatic Therapy*
◆ *Horsemanship Program*
◆ *Occupational/Vocational Therapy*
◆ *Contractual Employment for Residents*

Check Us Out! ☑

You'll be glad you did!

CONTACT US:
Beverly Farm Foundation
6301 Humbert Road
Godfrey, Illinois 62035
(618) 466-0367
E-mail: jhaycraft@beverlyfarm.org

Serving individuals with developmental disabilities since 1897

Circle #30 or visit www.eparent.com/adinfo

CANADIAN RESOURCES

ONTARIO

Georgian College
of Applied Arts & Technology
Barrie Campus
One Georgian Dr.
Barrie, ON
Canada L4M 3X9
(705) 728-1968
(705) 722-5123 (fax)

Kohai Educational Centre
41 Roehampton Ave.
Toronto, ON
Canada M4P 1P9
(416) 489-3636 (voice/fax)
✉kohai@sympatico.ca

Language Instruction
for Newcomers
to Canada (LINC)
100 Elm Dr. W., Rm. 114
Mississauga, ON
Canada L5B 1L9
(905) 270-6000
(905) 276-6797 (fax)
✉stnnes@net.clto.on.ca

EMPLOYMENT

ALBERTA

Centra Cam Vocational
Training Association
5502-46 St.
Camrose, AB
Canada T4V 1X4
(780) 672-9995
(780) 672-0534

Society For Selections
4209-99 St.
Edmonton, AB
Canada T6E 5V7
(780) 461-5270
(780) 463-8944 (fax)
✉select@connect.ab.ca

MANITOBA

Versatech Industries, Inc.
436 William Ave.
Winnipeg, MB
Canada R2Y 2C9
(204) 956-9700
(204) 943-1893 (fax)
✉vii@mb.aibn.com

NORTHWEST TERRITORIES

Disabled Persons
Work Strategy
PO Box 1170-5020-48 St.
Yellowknife, NT
Canada X1A 2N8
(867) 873-3560
(867) 920-7769 (fax)
✉rae.celotti@nt.sympatico.ca

ONTARIO

Injured Workers In Need, Inc.
560 Exmount St., Ste. 100A
Box 2466
Sarnia, ON
Canada N7T 2M0
(519) 344-6933
(519) 344-4257 (fax)

ODSP-Employment
Support Program
465 Davis Dr.
Newmarket, ON
Canada L3Y 8T2
(905) 868-8900
(905) 715-7662 (fax)

Project Work
2221 Yonge St., Ste. 100
Toronto, ON
Canada M4S 2B4
(416) 481-2211
(416) 481-2728 (fax)
✉gmacleod@projectwork.cnd.com

LIFEPLANNING

Planned Lifetime
Advocacy Network
Ste. 260-3665 Kingsway
Vancouver, BC
Canada V5R 5W2
(604) 439-9566
(604) 439-7001 (fax)

LITERACY

Kingston Literacy's Family
Literacy Program
88 Wright Crescent
Kingston, ON
Canada K7L 4T9
(613) 546-2580
(613) 547-2024 (fax)
✉kinglit@kos.net

OUTREACH AND SUPPORT

ALBERTA

Easter Seal Ability Council
400 10909 Jasper Ave.
Edmonton, AB
Canada T5J 3L9
(780) 429-0137
(780) 429-1937 (fax)
✉jodi@easter.ab.ca

Big Country Outreach Program
180 Riverside Dr.
Box 2547
Drumheller, AB
Canada T0J 0Y0
(403) 820-7260
(403) 823-2446 (fax)

Horizon School Council
c/o Horizon School
for Special Needs
5401-53 St.
Olds, AB
Canada T4H 1T3
(403) 556-6310
(403) 556-1640 (fax)
✉shorizon@telusplanet.net

Lethbridge Family Services
DaCapo Program
1107 2nd "A" North Ave
Lethbridge, AB
Canada T1H 0E6
(403) 320-9119
(403) 329-4924 (fax)
✉lfsdc@telusplanet.net
http://www.lethbridge-family-services.com

Lifestyle Choices
Box 2537
High Baird, AB
Canada T0G 1E0
(780) 523-2254
(780) 523-2254 (fax)
✉lc5101@telusplanet.net

Protegra, Inc.
#101 10212-127 Ave.
Edmonton, AB
Canada T5E 1V8
(780) 448-9390
(780) 472-7909 (fax)
✉nfrank@compusmart.ab.ca

The Vocational & Rehabilitation
Research Institute
3304 33rd St. NW
Calgary, AB
Canada T2L 2A6
(403) 284-1121
(403) 284-1146 (fax)
✉vrri@cadvision.com

Easter Seal Ability Council
103,811 Maming Rd Ne
Calgary, AB Canada T2E 7L4
(403) 235-5662
(403) 248-1716 (FAX)
✉slaw@telasplanet.net

BRITISH COLUMBIA

Cheshire Homes Society
of British Columbia
203, 5066 Kingsway
Burnaby, BC
Canada V5H 2E7
(604) 451-0686
(604) 451-0680 (fax)

Disability Resource Centre
160-5726 Minory Blvd
Richmond, BC
Canada V6X 2A9
(604) 232-2404
(604) 232-2415 (fax)
✉graphicl@direct.ca

Disability Services, Vancouver
Community College
City Centre Campus
250 W. Pender
Vancouver, BC
Canada V6B 1S9
(604) 443-8448
(604) 443-8588 (fax)

Office for Disability Issues
#100, 333 Quebec St.
Victoria, BC
Canada V8V 1X4
(800) 663-7867 (BC only)
(250) 387-3813
(250) 387-3555 (TDD)
(250) 387-3114 (fax)
http://www.disability.gov.bc.ca/

Resource Centre for Students
with a Disability
University of Victoria
PO Box 3015
Victoria, BC
Canada V8W 3P1
(250) 472-4947
(250) 472-4443 (fax)
✉plaliber@uvic.ca

Self-Help Resource
Association of BC
306-1212 W. Broadway
Vancouver, BC
Canada V6H 3V1
(604) 733-6186
(604) 730-1015 (fax)
✉shra@vcn.bc.ca

Skeena Family Resources
4734 Park Ave.
Terrace, BC
Canada V8G 1W1
(250) 635-7087
(250) 635-7095 (FAX)
✉skeenafamily@kermode.net

Society of Special Needs
Adoptive Parents
1150-409 Granville St.
Vancouver, BC
Canada V6C 1T2
(604) 687-3114
(604) 687-3364 (fax)
✉snap@snap.bc.ca

Step by Step Child
Development Society
200-2232 McAllister Ave.
Port Coquitlam, BC
Canada V3C-2A6
(604) 552-0896
✉stepbystep@telus.net

Western Society for Children
with Birth Disorders
317 Columbia St., #102-317
New Westminster, BC
Canada V3L 1A7
(604) 515-0810
(604) 515-0870 (fax)
✉chldstrt@axionet.com

MANITOBA

Manitoba League of Persons
with Disabilities 2000
105-500 Portage Ave.
Winnipeg, MB
Canada R3C 3X1
(204) 943-6099 (voice/TDD)
(204) 943 3146 (fax)
✉mlpd@mb.sympatico.ca
http://www.mlpd.mb.ca

Pregnancy Distress Family
Support Services, Inc.
571 Furby St.
Winnipeg, MB
Canada R3B 2V9
(204) 772-9091
(204) 774-2161 (fax)
✉distress@pangea.ca

Rehabilitation Centre for Children
633 Wellington Crescent
Winnipeg, MB
Canada R3M 0A8
(204) 452-4311
(204) 477-5547 (fax)

Youth Emergency Crisis
Stabilization System
Macdonald Youth Services, Inc.
226 St. Mary's Rd.
Winnipeg, MB
Canada R2H 1J3
(204) 949-4750
(204) 949-4776 (fax)
✉dsullivan@mys.mb.ca

NEW BRUNSWICK

Family Support Services
236 St. George St. Suite 315
Moncton, NB
Canada E1C 1W1
(506) 869-6977
(506) 853-7856 (fax)

New Brunswick Easter Seal March
of Dimes
65 Brunswick St.
Fredericton, NB
Canada E3B 1G5
(506) 458-8739
(506) 457-2863 (fax)
✉esmobdnbnb@nb.aib.com

Respite Care Services for Children
with Special Needs
236 rue St. Georges
local 315
Moncton, NB
Canada E1C 1W1
(506) 853-7856 (fax)
✉mctnvol@nbnet.nb.ca

NEW FOUNDLAND

Newfoundland & Labrador
Interpreting Service
220 Lemarchant Rd.
Ste. 301
St. John's, NF
Canada A1C 2H8
(709) 753-5621
(709) 753-5620 (TDD)
(709) 753-5682 (fax)
✉nlis@nfld.com

NORTHWEST TERRITORIES

NWT Council
for Disabled Persons
Box 1387
Yellowknife, NT
Canada X1A 2P1
(861) 873-8230
(867) 873-4124 (fax)
✉eiream@tamarack.nt.ca

Status of Women Council
of the NWT
PO Box 1320
Yellowknife, NT
Canada X1A 2L9
(867) 920-6177
(867) 873-0285 (fax)
✉council@statusofwomen.nt.ca
http://www.statusofwomen.nt.ca

NOVA SCOTIA

Bridgeway Academy Association
94 Crichton Ave.
Dartmouth, NS
Canada B3A 1R4
(903) 464-0134
(903) 464-0134 (fax)
✉bridgeway.academy@ns.sympatico.ca

ONTARIO

The Barrie & District Association
PO Box 1119
(39 Fraser Ct.)
Barrie, ON
Canada L4M 5E2
(705) 726-9082
(705) 726-6875 (fax)
✉lprice@bdapsn.on.ca

Best Buddies Canada
2333 Dundas St. W., Ste. 210
Toronto, ON
Canada M6F 1F9
(416) 531-0003
(416) 531-0325 (fax)
✉bestbuddiescanda@yahoo.com

Canadian Injured
Workers Alliance
P.O. Box 10098
Thunder Bay, ON
Canada P7B 6T6
(807) 345-3429
(807) 344-8683 (fax)
✉ciwa@norlink.net

C.H.A.N.G.E.S.
Peterborough and Area Down
Syndrome Support Group
360 George St. N.,
Peterborough Square Unit 24
Peterborough, ON
Canada K9J 6Y2
(705) 749-6695
(705) 749-5864 (fax)
✉changes@pipcom.com
http://www.aboutchanges.com

Children's Integration Support Services
Ste. 600-700 Industrial Ave.
Ottawa, ON
Canada K1G 0Y9
(613) 736-1913 ext.229
(613) 736-8378 (fax)
✉ciss@afchildcare.on.ca

Consumer/Survivor Information Resource Centre of Toronto
c/o Day Centre, CAMH,
252 College St.
3rd Floor
Toronto, ON
Canada M5T 1R8
(416) 595-2882
(416) 595-0291 (fax)
✉csinfo@icomm.ca

Epilepsy Cornwall & Area
309 Anne St.
Cornwall, ON
Canada K6J 3E9
✉marcel.aube2@sympatico.ca

ERINOA Serving Young People with Physical Disabilities
2277 South Millway
Mississauga, ON
Canada L5L 2M5
(905) 820-7111
(905) 820-1333 (fax)
✉galexandrova@erinoak.org

Extend-A-Family
74 Queen St. N
Kitchener, ON
Canada N2H 2H3
(519) 741-0190
(519) 741-0392 (fax)
✉mdeboer@eafwr.on.ca

Hamilton Family Network
22 Leeming St.
Hamilton, ON
Canada L9H 4G2
(905) 526-7190
(905) 526-0767
✉hamiltonfamilynetwork@hwcn.org

ISAAC-International Society for Augmentative and Alternative Communication
49 The Donway West #308
Toronto, ON
Canada M3C 3M9
(416) 385-0351
(416) 385-0352 (fax)
✉secretariat@isaac-online.org

National Clearinghouse on Family Violence
7th Fl., Jeanne Mance Bldg.
Tunney's Pasture 190 7D1
Ottawa, ON
Canada K1A 1B4
(800) 267-1291
(613) 941-8930 (fax)
http://www.nc-sc.gc.ca/nc-cn

National Service Dogs
PO Box 25
Peterburg, ON
Canada N0B 2H0
(519) 662-4223
(519) 662-4697
✉info@nsd.on.ca

The Ottawa Rotary Home
30 Rochester St.
Ottawa, ON
Canada K1R 7V3
(613) 236-3200
(613) 236-0334 (fax)
✉info@rotaryhome.on.ca

Resources for Exceptional Children
865 Westney Rd. South
Ajax, ON
Canada L1S 3M4
(905) 427-8862
(905) 427-9615 (fax)

SD&G Developmental Services Centre
1 McConnell Ave.
Cornwall, ON
Canada K6H 4K8
(613) 937-3072
(613) [illegible]37-4550 (fax)
✉fi[illegible]d2.glen-net.ca

Special Needs Opportunity Windows (SNOW)
University of Toronto
Information Commons Adapt.
Tech Resource
130 St. George St.
Toronto, ON
Canada M5S 3H1
(416) 978-4360
(416) 971-2629 (fax)
✉snow.general@utoronto.ca

Starlight Children's Foundation
250 Consumers Rd., Ste. 1101
Willowdale, ON
Canada M2J 4V6
(416) 502-9474
(416) 502-9477 (fax)
✉laura@starlightcanada.org

University of Toronto at Scarborough AccessAbility Services
1265 Military Trail
Scarborough, ON
Canada M1C 1A4
(416) 287-7553
(416) 287-7334 (fax)
✉ability@scar.utoronto.ca

10 Friends Diner
1000 Drouillard Rd.
Windsor, ON
Canada N8Y 2P8
(519) 254-3000
(519) 252-4291 (fax)

QUEBEC

Aceveil et Integration des Personnes Handicapees Etudiantes
Pavillon Maurice Pollack,
Bureau 2121
Universite Laval, QC
Canada G1K 7P4
(418) 656-2880
(418) 656-7866 (fax)

continued on page 178

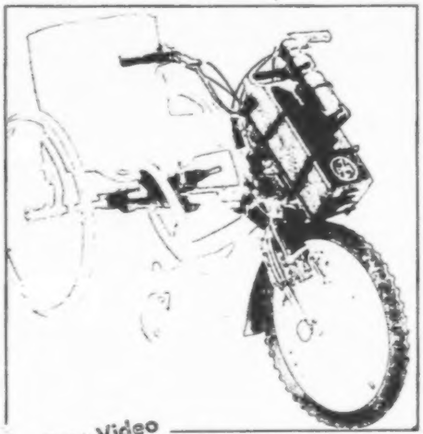
PT1000 PowerTrike™ Features

Makes a Great Gift!

Introducing the **PT1000 PowerTrike™** offered by **Harmar Mobility.** Simply connect the **PowerTrike™** to virtually any wheelchair and it turns into a powerful new form of electric transportation. A range of 15 to 20 miles between charges makes the **PowerTrike™** a useful tool for everyday tasks as well as a fun recreational vehicle. Firm sand, fields, offroad paths and other walkways are not only accessible but fun with the powerful and versitile **PowerTrike™**. Boldly go where few wheelchairs have gone before.

pdq®

PowerTrike™ owners enjoy the benefits of free membership to the pdq Club for one year. A pdq Club member automatically qualifies for free insurance to protect against accidental damage, theft and even a breakdown of the **PowerTrike™** and/or the wheelchair in addition to other benefits.



- Dual Front Brakes and Twist Throttle
- Digital Speedometer & Clock
- Speed up to 11 mph
- Quick Release Gel Battery
- 2 Speed Control Box & Battery Level Indicator
- Quickly and Easily attaches to Folding and Sport Chairs
- Powerful 150 watt brush motor
- 20" Wheel for Rough Terrain
- Range - 15 to 20 Miles per charge

Free Video available on VHS or CD ROM

800-833-0478 • www.harmar.com

HARMAR MOBILITY

Circle #70 or visit www.eparent.com/adinfo

For Family Freedom
Get a Superarm Lift

Handicaps, Inc.

- Quick installation
- Doesn't Block Door
- 3 Year waranty
  5 year limited
- Less Cost
- V.A. tested
- Load in seconds
- Less Parking Space

"We are absolutely delighted with the Superarm Lift. The major advantage is the ease and unobtrusiveness with which it mounts to the van. It is so much more attractive than the various elevator contraptions. The lift has increased our son's mobility by 100%. We enthusiastically recommend the Superarm Lift."
Mr & Mrs Crowl - Tulsa, OK

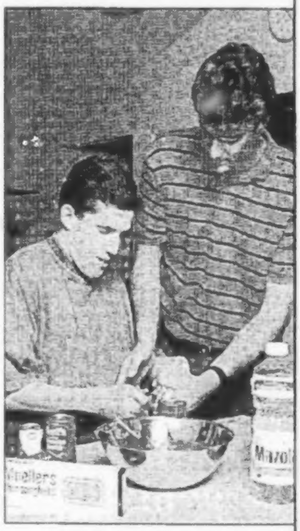
- **Fits full-size vans, RV's & some mini-vans *(ask us)***
- **Lifts Electric & Manual chairs *tell us if you have seat inserts***

Visa and MasterCard accepted
Call or write for a free brochure

4335 So. Santa Fe Dr.,
Englewood, CO 80110
Fax. (303) 761-6811

1-800-782-4335
www.handicapsinc.com

Circle #68 or visit www.eparent.com/adinfo



LIVING & LEARNING

STUDENTS AT THE EVERGREEN CENTER learn to live in the community and reach their full potential. Our Basic Skills and Behavior Development Centers, community residence programs and supportive staff combine to create a caring environment allowing students to achieve a greater degree of personal independence.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631

Serving students with developmental, medical and behavioral needs since 1981.

Circle #56 or visit www.eparent.com/adinfo

Getting information from EP advertisers is

MUCH FASTER ONLINE!

It's as easy as a click of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

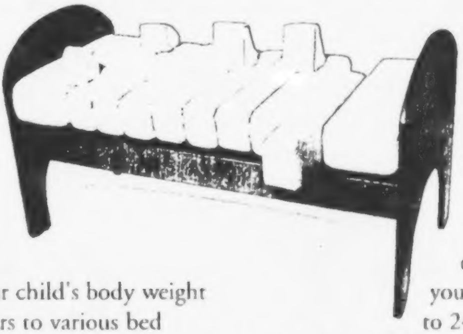
WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

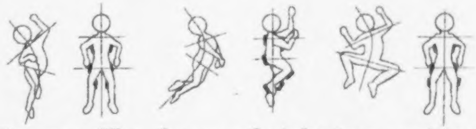
Nighttime Positioning You No Longer Have To Dream About.



Introducing Dreama™, a unique and innovative sleep system from Jenx that provides your child with better positioning throughout the night.

The Dreama™ concept utilizes a series of specially-compounded foam blocks that firmly position and support your child's body weight individually. The system contours to various bed frames and quietly adjusts to support the body in any position—supine, prone, and side lying. Dreama™ positions a child to prolong sleep patterns and prevent stiffness and aspiration.

Putting your child down for the night in Dreama™ extends the optimum positioning you achieved throughout the day to 24 hours. Give your child the relaxation and sweet dreams they need so much.

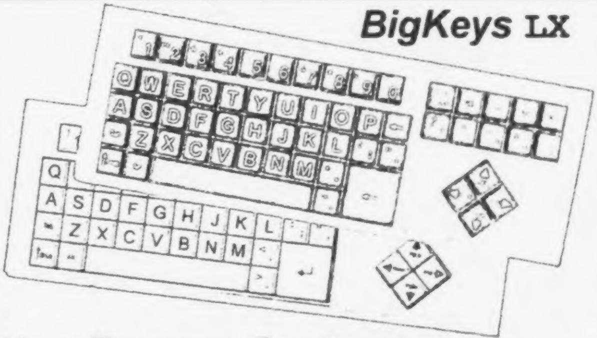


Dreama. The dream of nighttime positioning.

JENX
Distributed by
BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #34 or visit www.eparent.com/adinfo

BigKeys LX



New Reverse Contrast

Large white letters on new black 1-inch keys for improved contrast.

All the function and punctuation keys you need without the clutter! **Easy to see and easy to use.**

The built-in 'Assist Mode' allows complete use with one hand, one finger or pointer device.

For all PC/Windows computers.

Greystone Digital Inc
PO BOX 1888
Huntersville NC 28078

TEL 800-249-5397
FAX 704-875-8936

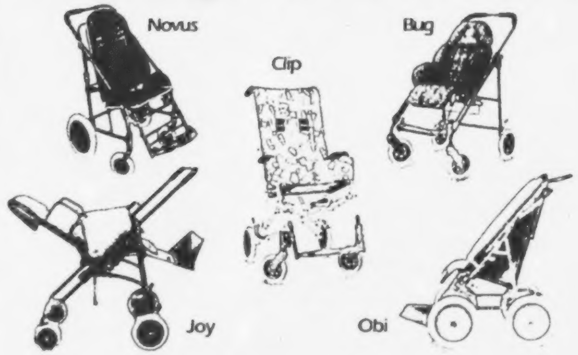
www.bigkeys.com

Circle #65 or visit www.eparent.com/adinfo

Mr. Mobility
proudly introduces...

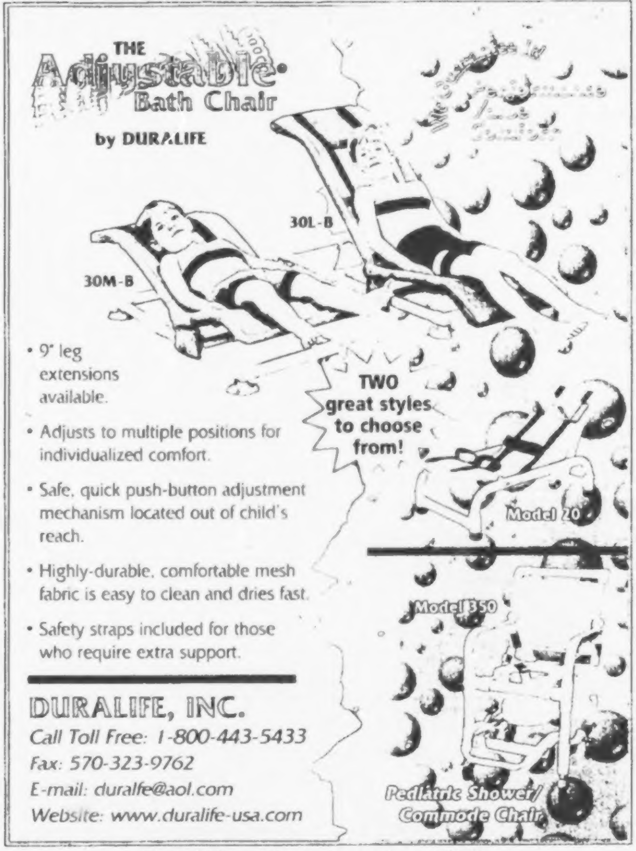
ORMESA
STROLLERS

IMPORTED FROM ITALY



For more information call
1-800-555-2909
www.mrmobility.com

Circle #46 or visit www.eparent.com/adinfo


30L-B
30M-B
TWO great styles to choose from!
Model 20
Model 350
Pediatric Shower/ Commode Chair

THE
Adjustable® Bath Chair
by DURALIFE

- 9" leg extensions available.
- Adjusts to multiple positions for individualized comfort.
- Safe, quick push-button adjustment mechanism located out of child's reach.
- Highly-durable, comfortable mesh fabric is easy to clean and dries fast.
- Safety straps included for those who require extra support.

DURALIFE, INC.
Call Toll Free: 1-800-443-5433
Fax: 570-323-9762
E-mail: duralfe@aol.com
Website: www.duralife-usa.com

Circle #52 or visit www.eparent.com/adinfo

Multi-Sensory Environments

Let TFH (USA) . . . .
assist you in creating a **Multi-Sensory Environment** which can provide valuable therapy for individuals who have various sensory, cognitive, and physical disabilities. Provide your child with a unique sensory area that can bring **Relaxing, Stimulating,** or **Interactive** experiences into their life. Sensory environments can be uniquely designed for your child, or you can utilize TFH's mobile **VECTA** unit, which can easily transform a small room into a sensory area.

Contact TFH (USA) for more Information

We offer: Personalized Attention
Free MSE Consultation
MSE Video & Informational Materials
Excellent Customer Service

T.F.H. (USA) Ltd. - 4537 Gibsonia Road - Gibsonia, PA 15044

tfh Have a Sensory Experience

Phone: (724) 444-6400
Toll Free: 1-800-467-6222
Fax: (724) 444-6411

Circle #124 or visit www.eparent.com/adinfo

est. 1978
Consumer Care™
Rehab Specialties Division

Special Purpose Products for Special Persons and Those Who Assist Them

See Our New & Expanded Catalog on Adults & Children

Quality crafted
in the USA

VISIT Our Easy To Use & Fast Access Web Site
www.consumercareinc.com

- See & Learn about Products & 3M Supplies
- Obtain Dealer Referrals
- Positioning Management Programs
- Lease/Rental Options
- Trial Use/Evaluations
- News & Valuable Tips

Consumer Care Products Inc. Rehab Speciality Division
1446 Pilgrim Road, Plymouth, WI 53073, U.S.A.
Tel: 920-893-4614 or FAX: 920-893-6195
E-Mail: ccpi@consumercareinc.com

Circle #43 or visit www.eparent.com/adinfo

NIMH National Institute of Mental Health

Participate in exciting research at the National Institute of Mental Health

Children with Spastic Diplegia

What is the purpose of the study?
To study how Cerebral Palsy affects eye-hand coordination

What are the requirements?
Children must be 6-16 years of age, have a diagnosis of Spastic Diplegia, and be available for four sessions of 2-3 hours

Some information about the study:
Patients will receive:
- Neurological Exam
- Neuropsychological/ neuromotor testing
- Magnetic Resonance Imaging (MRI of the brain)
- EMG using surface electrodes
- EEG using surface electrodes

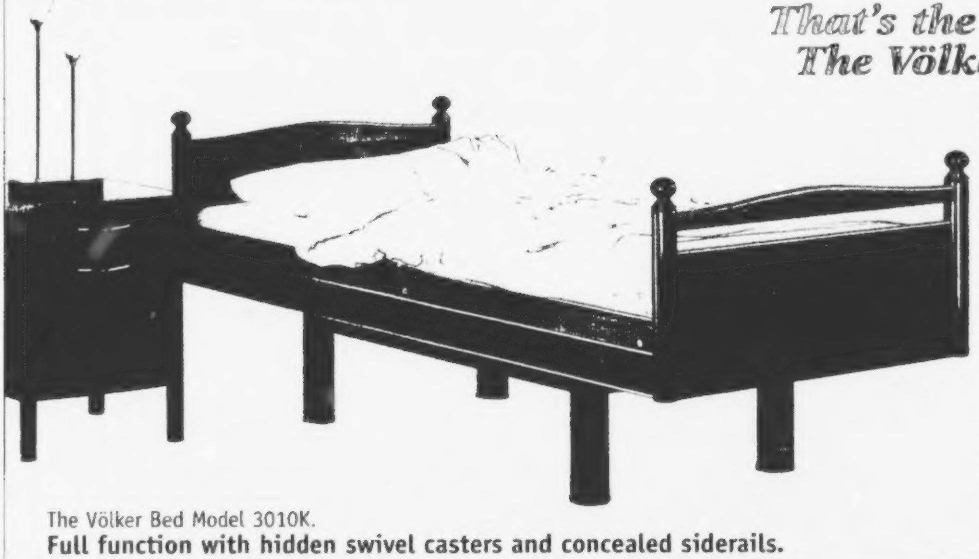
All procedures are non-invasive, no needles
Compensation is provided

If you are interested, please contact
Dr. Marjorie Garvey
or
Elizabeth Redcay, Research Assistant
(301) 496-5323
Pediatric and Developmental Neuropsychiatry Branch
National Institute of Mental Health

Circle #96 or visit www.eparent.com/adinfo

VÖLKER **The health-care bed in disguise.**

That's the beauty of The Völker Style ...



Beautiful homelike appearance of fine furniture — with the features you've asked for:

- **Concealed siderails**
- **4 hidden swivel casters**
- Height adjustable
- Head and leg adjustment
- Secure electric braking system

The Völker Bed Model 3010K.
Full function with hidden swivel casters and concealed siderails.

For more information call 1-800-321-4240
Also ask about our low-height options.
Visit our Web site at **www.hertzsupply.com**

Hertz SUPPLY

Circle #72 or visit www.eparent.com/adinfo

We Accept Medicare, Medicaid & Private Insurances

No Upfront Costs!!!
No Paperwork!!!
We Bill Your Insurance Company

Free Home Delivery

- Manual & Power Wheelchairs
- Hospital Beds & Hoyer Lifts
- Ostomy Supplies/Wound Care
- Examination Gloves
- Diapers & Underpads
- Commodes
- Walkers, Canes, Crutches
- Back & Knee Supports
- Diabetic Supplies
- Nebulizers & Humidifiers

- Oxygen - 24-Hour Emergency Service
- Full Mastectomy Boutique
- Specialized Wheelchairs & Seating Systems
- Vehicle Lifts & Stair Lifts

Phone: 845-794-2323
1-800-282-6334
www.medifair.com
or 845-343-3003

Medi-Fair
Home Healthcare Equipment

• Exit 104 Rt. 17 Quickway
Monticello, New York 12701
• Rt 211, Middletown, NY

Circle #90 or visit www.eparent.com/adinfo

SING ALONG

TIME To SING!

Give the gift of song with *Time to Sing!* *Time to Sing!* is a newly arranged children's music CD with 26 of your child's favorite songs. The tempo is slowed down to enable children with speech and other disabilities to sing along. Preschool teachers, speech pathologists and parents agree: children *love* to sing with *Time to Sing!*

To order, call 1-800-795-8747
Or visit the Center for Creative Play's online shop at www.center4creativeplay.org

Circle #48 or visit www.eparent.com/adinfo

CANADIAN RESOURCES

continued from page 178

Communications & Centre de Documentation/Resource Centre
Canadian HIV/AIDS Legal Network
417,rue McGill, Suite 408
Montreal, QC
Canada H2Y 2H4
(514) 397-6828
(514) 397-8570 (fax)
✉thaig@aidlaw.ca
http://www.aidslaw.ca

West Island Citizens Advocay
68 Prince Edward Pte.
Claire, QC
Canada H9R 4C7
(514) 694-5850
(514) 694-1867 (fax)
✉wica@qc.aibn.com

SASKATCHEWAN

Saskatchewan Office of Disabilty Issues
1920 Broad St.
Regina, SK
Canada S4P 3V6
(306) 787-7283
(306) 798-0364 (fax)
✉odi.ss@govmail.gov.sk.ca

PUBLICATIONS

Abilities Magazine/Canadian Abilities Foundation
489 College St., Ste. 501
Toronto, ON
Canada M6G 1A5
(416) 923-1885
(416) 923-9829 (fax)
✉able@abilities.ca

"We're Accessible"
Travel News
128-10125-156th St.
Surrey, BC
Canada V3R 0E7
(604) 588-3731
(604) 588-3731 (fax)
✉wereaccessible@home.com

RECREATION

ALBERTA

Alberta Amputee Sports & Recreation Association (AASRA)
PO Box 780, Station M
Calgary, AB
Canada T2P 2J3
(403) 201-0507
(403) 256-7611 (fax)
✉info@aasra.ab.ca

Alberta Cerebral Palsy Sports Association (ACPSA)
Percy Page Centre,
11759 Groat Rd.
Edmonton, AB
Canada T5M 3K6
(780) 422-2904
(780) 422-2663 (fax)
✉acpsa@telusplanet.net

Alberta Special Olympics
11759 Groat Rd.
Percy Page Center
Edmonton, AB
Canada T5M 3K6
(780) 415-0719
(780) 422-2663 (fax)
✉aso@nucleus.com

High River Therapeutic Riding Association
Judith Dornan
Box 21 Sites R.R #2
Okotoks, AB
Canada T0L 1T0
(403) 938-2587
(403) 938-2537 (FAX)

BRITISH COLUMBIA

BC Special Olympics
#226-1367 W. Broadway
Vancouver, BC
Canada V6H 4A9
(604) 737-3078
(604) 737-3080 (fax)
✉specialolympics@bcso.bc.ca

BC Disability Sports
322-1367 W. Broadway
Vancouver, BC
Canada V6H 4A9
(604) 737-3039
(604) 737-3035 (fax)
✉dissport@disabilitysport.org

Burnaby Parks Recreation and Cultural Services
101-4946 Canada Way
Burnaby, BC
Canada V5G 4H7
(604) 294-7168
(604) 294-7201 (fax)

Canadian Association for Disabled Skiing
Box 307
Kimberly, BC
Canada V1A 2Y9
(250) 427-7712
(250)427-7715 (fax)
✉cads@rockies.net
http://www.disabledskiing.ca

Cowichan Therapeutic Riding Association
1843 Tzouvhalem Rd.
Duncan, BC
Canada V9L 5L6
(250) 746-1028
(250) 746-1033 (fax)
✉ctra@seaside.net

Delta Parks Recreation & Culture
4600 Clarence Taylor Crescent
Delta, BC
Canada V4K 3X3
(604) 946-3288
(604) 946-8614 (fax)
✉ckelly@corp.delta.bc.ca

North Okanagan Therapeutic Riding Association
Box 328
Vernon, BC
Canada V8T 6M3
(250) 549-0105
(250) 546-4171 (fax)
✉notra@mybc.ca

MANITOBA

Wild-Wise Wilderness Adventures
230 Sherbrook St.
Winnipeg, MB
Canada R3C 2B6
(204) 788-1070
(204) 788-1001 (fax)
✉wildwise@pangea.ca

ONTARIO

Camp Awakening, Inc.
150 Eglinton Ave. E., 204
Toronto, ON
Canada M4P 1E8
(416) 487-8400
(416) 486-3854 (fax)
✉awake@visinet.ca
http://www.campica/awakening

Canadian Cerebral Palsy Sports Association
1010 Polytek St., Unit 2 2nd Floor
Gloucester, ON
Canada K1J 9H9
(613) 748-1430
(613) 748-1355 (fax)
✉ccpsa@cyberus.ca

CARD Community Association of Riding for the Disabled
4777 Dufferin St.
Toronto, ON
Canada M3H 5T3
(416) 667-8600
(416) 739-7520 (fax)
✉card@volnetmmp.net
http://www.card.ca

Central Ontario Developmental Riding Program
584 Pioneer Tower Rd.
Kitchener, ON
Canada N2P 2H9
(519) 653-4686
(519) 653-5565 (fax)
✉codrp@sentex.net
http://www.codrp.com
http://www.pridestables.com

Lamark County Therapeutic Riding Program
103 Judson St.
Carleton Place, ON
Canada K7C 4F5
(613) 257-7121
(613) 257-2675 (fax)
✉scfessy@iss.net

PRANCE
Pegasus Riding Association Nuturing Challenged Equestrians
Miramichi Farms (Box 2037)
Port Elgin, ON
Canada N0H 2C0
(519) 832-2522
(519) 832-2139 (fax)
✉prance@bmts.com

Recreation and Parks
Diana Simpson Recreation Analyst, Seniors
300 City Centre Drive
Mississauga, ON
Canada L5B 3C1
(905) 615-3469
(905) 615-3936 (fax)
✉diana.simpson@city.mississauga.on.ca

Tennis Canada
3111 Steeles Ave. W.
Downsview, ON
Canada M3J 3H2
(519) 624-6399
(519) 624-6401 (fax)
✉jpetras@hotmail.com

Variety Village
3701 Danforth Ave.
Toronto, ON
Canada M1N 2G2
(416) 699-7167
(416) 699-5752 (fax)
✉aallison@varietyvillage.on.ca

WindReach Farm
312 Townline Rd.
Ashburn, ON
Canada L0B 1A0
(905) 655-5827
(905) 655-5652 (fax)
✉windreach@sympatico.ca
http://www.windreach.org

SASKATCHEWAN

Saskatchewan Wheelchair Sports Association
510 Cynthia St.
Saskatoon, SK
Canada S7L7K7
(306) 975-0824
(306) 975-0825 (fax)

RESEARCH

MANITOBA

Canadian Centre on Disability Studies
56 The Promenade
Winnipeg, MB
Canada R3B 3H9
(204) 287-8411
(204) 284-5343 (fax)
✉ccds@escape.ca
http://www.escapre.ca/~ccds/

Universal Design Institute/ Faculty of Architecture
201 Russel Bldg.
University of Manitoba
Winnipeg, MB Canada R37 2N2
(204) 474-8588
(204) 474-7532 (fax)
✉universal_design@umanitoba.ca

ONTARIO

The Roeher Institue
Roslyn Ward
Kinsnen Building York University
4700 KeeleStreet
Toranto ON Canada N3J 1P3
(406) 661-9611
(406) 661-5701 (fax)
✉info@roeher.ca

NEWFOUNDLAND

Trinity Conception Placentia Health Foundation
86 Highroad S.
Carbonear, NF
Canada A1Y 1A4
(709) 945-5289
(709) 945-5158 (fax)
✉money@achib.nf.net

SPECIFIC DISABILITIES

AIDS/HIV

Alberta Community Council on HIV
203, 5000-50th Ave.
Red Deer, AB
Canada T4N 6C2
(403) 346-8858
(403) 346-2352 (fax)
✉acch@idmail.com

AIDS & Disability Action Program (ADAP)/Wellness & Disability Initiative (WDI)
204-456 W. Broadway
Vancouver, BC
Canada V5Y 1R3
(877) 232-7400 (Toll Free)
(604) 875-9227 (fax)
✉wdi@bccpd.bc.ca
http://www.bccpd.ca/wdi

Feather of Hope Aboriginal AIDS Prevention Society
702, 10242-105 St.
Edmonton, AB Canada T5J 3L5
(800) 256-0459
(780) 488-5773
(780) 421-9004 (fax)
✉fohaaps@compusmart.ab.ca
http://www.featherofhope.org

Peterborough AIDS Resource Network
Joanne Lush
159 King St Suite 302
Peterborough, ON
Canada K9J 2R8
(705) 749-9110
(705) 749-6310 (FAX)
✉parn@kawartha.com

AICARDI SYNDROME

Aicardi Syndrome Awareness & Support Network
29 Delavan Ave.
Toronto, ON
Canada M5P 1T2
(416) 481-4095

ALZHEIMER'S DISEASE

Alzheimer Society of Manitoba- Westman
437 9th St.
Brandon, MB
Canada R7A 4A9
(204) 729-8320
(204) 726-1082 (fax)
✉alzwm@escape.ca

Saint John Alzheimer Society Inc.
152 Westmorland Rd.
Saint John, NB
Canada E2J 2E7
(506) 634-8722
(506) 648-9404 (fax)

AMYOTROPHIC LATERAL SCLEROSIS (LOU GEHRIG'S DISEASE)

ALS Society of Saskatchewan
PO Box 31028
Normanview Mall
Regina, SK
Canada S4R 8R6
(306) 949-4100
(306) 949-4020 (fax)

ARTHRITIS

The Arthritis Society
393 University Ave., Ste. 1700
Toronto, ON
Canada M5G 1E6
(416) 979-7228
(416) 979-8366 (fax)
✉vdesrocher@arthritis.ca

Arthritis Society Consultation and Rehabilitation Service
#200, 73 N. Cumberland St.
Thunder Bay, ON
Canada P7A 4L8
(807) 344-1950
(807) 344-1950 (fax)
✉tbcars@tbaytel.net

AUTISM

Autism Resource Centre
P.O Box 4751
Regina, SK
Canada S4P 3Y9
(306) 569-0858
(306) 569-0889

Autism Society of BC
301-3701 E. Hastings
Burnaby, BC
Canada V5C 2H6
(604) 434-0880
(604) 434-0801 (fax)
✉librarian@autismbc.ca

Autism Society Manitoba
825 Sherbrook St., Rm. 204
Winnipeg, MB
Canada R3A 1M5
(204) 783-9563
(204) 975-3027 (fax)
✉asm@escape.ca

Autism Society of Newfoundland and Labrador
Susan Tobin
P.O. Box 14078 Station 'A'
St. John's ,NF Canada A1B 4G8
(709) 722-2803
(709) 722-4926 (FAX)
✉info@autismsociety.nf.net or
✉kmacdonald@roadrunner.nf.net

continued on page 180

ABLEWARE®

KiD STUFF

Family Toilet Seat

The perfect seat for children and adults.

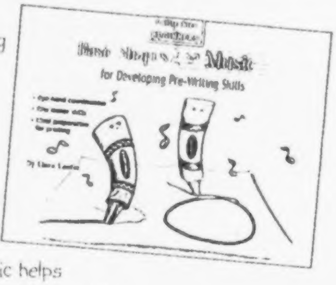
Features a child's seat, with a smaller opening, fitted between a standard adult toilet seat and lid. When not in use, the child's seat can be flipped up and nestled into the recess of the lid and it can be removed for easy cleaning or storing.

Fits all standard toilets.

F72620-0000 **$59.95**

U.S. Patent #4,461,046

Callirobics™ Handwriting Exercises - For Beginners



Basic shapes to music for developing pre-writing skills for children just starting to experiment with "writing" or for children with low developmental ability. Upbeat music helps to develop a comfortable rhythm.

Includes exercise guide and audiocassette of musical selections.

F71744-0004 **$22.35**

For more info or a complete catalog contact:

Maddak Inc. 6 Industrial Rd. • Pequannock, NJ 07440-1993 USA • 973-628-7600 • fax 973-305-0841
email custservice@maddak.com • www.maddak.com

Circle #86 or visit www.eparent.com/adinfo

Every kid should have a bike to ride...

Top End XLTjr

Kid tested...

100% Awesome!

Feel the magic!

... I wanted to let you know that my son Jason is enjoying his handcycle very much... He is so happy to be out riding with his brothers and sisters... Fantastic customer service. You were great!
Laura Connor
Perris, California

...Thank you for your help in getting my 8 year old grandson a handcycle. He was just totally thrilled with it, as were the rest of us...
Barbara Warren
Moore, OK

bike-on.com

Call bike-on.com
at 1-888-4bikeon
or 401-821-7544

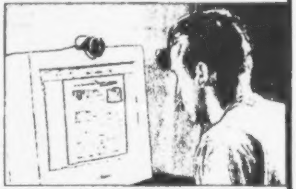
The Handcycle Store www.bike-on.com

Circle #31 or visit www.eparent.com/adinfo

Life is now easier for people with restricted mobility.

Introducing miracle mouse™
The Ultimate Controller for People with Restricted Mobility

Get Complete Control of your Computer – Hands Free!



Clicking and double clicking are easy!

Miracle Mouse is the revolutionary headgear controller that gives people with mobility limitations complete control of their PC – hands free! Imagine being able to retrieve lists of words and phrases that can be inserted into any Microsoft application using a single head movement – *no switches or mouth-controlled devices required.* Miracle Mouse makes it easy for anyone to send and receive email, surf the Internet, word process, program a web site, play games, and more!

For more information or to buy now:

www.miracle-mouse.com • 866-875-5556 (Toll-Free)

Highlighted Features:

- Extremely accurate
- Adjustable sensitivity
- Customizable on-screen keyboard
- Lightweight with no moving parts
- Profiling software allows complete mouse emulation
- Works with other controllers and assistive products
- USB ready

BUY NOW!

MAUi™
innovative peripherals inc.
www.maui-innovative.com

Circle #89 or visit www.eparent.com/adinfo

CANADIAN RESOURCES

continued from page 178

Autism Treatment Services
of Saskatchewan, Inc.
#302-506 25th Street East
Saskatoon, SK Canada 57K 4A7
(306) 665-7013
(306) 665-7011 (fax)
✉atss.sktn@home.com
http://www.autism-atss.com

Gateway Society-Services
for Persons with Autism
4807 Georgia St.
Delta, BC
Canada V4K 1P4
(604) 946-0401
(604) 946-8429 (fax)

Ottawa Valley Autistic Homes
(OVAH)
Ste. 200-235 Donald St.
Ottawa, ON
Canada K1K 1N1
(613) 746-2722
(613) 746-2773 (fax)
✉prgmdir@ovah.on.ca

Society for Treatment
of Autism (NS)
541 Charlotte St./PO Box 392
Sydney, NS
Canada B1P 6H2
(902) 567-6441
(902) 567-0425 (fax)
✉autism@auracom.com

BRAIN INJURY

Brain Injury Association of
Chatham-Kent
463 St. Clair St., Ste. 3B
Chatham, ON
Canada N7L 3K6
(519) 351-0297
(519) 351-7600 (fax)
✉biack@ciaccess.com
http://www.biack.com

Brain Injury Services
of Northern Ontario
185 South Court St.
Thunder Bay, ON
Canada P7B 2X7
(807) 345-1188
(807) 345-1428 (fax)
✉bisnoro@air.on.ca

Central Okanagan
Brain Injury Society
100-532 Leon Ave.
Kelowna, BC
Canada V1Y 6J6
(250) 762-3233
(250) 861-3008 (fax)
✉cobisadmin@home.com

Friends of the Head Injury
Association (FOTHI)
c/o Central Lions Centre
11113-113 St.
Edmonton, AB
Canada T8N 1M9
(780) 967-2468 (phone/fax)
http://www.fothi.com

CEREBRAL PALSY

Cerebral Palsy Assocation
of Manitoba
1060 Ellice Ave.
Winnipeg, MB
Canada R3G 0C9
(204) 982-4811
(204) 982-4844 (fax)
✉office@cerebralpalsy.mb.ca

CHARCOT-MARIE-TOOTH DISEASE

CMT International
1 Springbank Dr.
St. Catharanes, ON
Canada L2S 2K1
(905) 687-3630
(905) 687-8753 (fax)

CHRONIC FATIGUE SYNDROME & FIBROMYALGIA

National ME/FM Action Network
3836 Carling Ave.
Nepean, ON
Canada K2K 2Y6
(613) 829-6667
(613) 829-6667 (fax)

CYSTIC FIBROSIS

Canadian Cystic Fibrosis
Foundation-Scotia Chapter
PO Box 27175
Halifax, NS
Canada B3H 4M8
(902) 425-2462

DEVELOPMENTAL DISABILITIES

Children's Health and
Developmental Services
(CHADS)
666 5th St. SW
Medicine Hat, AB
Canada T1A 4H6
(403) 529-8966
(403) 529-8859 (fax)

Developmental Services
of Leeds and Greenville
PO Box 1688
Brockville, ON
Canada K6V 6K8
(613) 345-1290
(613) 345-1685 (fax)
✉dslg@recorder.ca

L'Arche Cape Breton
General Delivery
Whycocomagh, NS
Canada B0E 3M0
(902) 756-3162
(902) 756-3381 (fax)
✉larchecb@atcon.com
http://www.larchecapebreton.com

Mental Health and Disabilities
Program, Mennonite Central
Committee, Canada
134 Plaza Dr.
Winnipeg, MB
Canada R3T 5K9
(204) 261-6381 x221
(204) 269-9875 (fax)
✉ikj@mennonitecc.ca

Peel Caring Network for
Challenged Kids
5806 Turney Dr.
Mississauga, ON
Canada L5M 2R8
(905) 858-9591
✉CLERUN@HOME.com

West Island Association for the
Intellectually Handicapped
111 Donegan
Pointe Claire, QC
Canada H9R 2W3
(514) 694-7090
(514) 694-5839 (fax)
✉wiaih@axess.com

Winnifred Stewart Association
11130-131 St.
Edmonton, AB
Canada T5M 1C1
(780) 453-6707
(780) 453-6709 (fax)
✉info@winnifredstewart.com
http://www.winnifredstewart.com

DIABETES

Canadian Diabetes Association
Box 1412
#120-540 Seymour St.
Kamloops, BC
Canada V2C 6L7
(250) 374-5744
(250) 374-7964 (fax)
✉cda_kamloops@telus.net

Canadian Diabetes Association
Parkland Region
118 Main St. N.
Dauphin, MB
Canada R7N 1C2
(204) 638-6248
(204) 638-6248 (fax)
✉catherine.kingsley@diabetes.ca

Trillium Health Centre/Paediatric
Diabetes Centre
100 Queensway W.
Mississauga, ON
Canada 5B 1B8
(905) 848-7580 ext.3410
(905) 804-7741 (fax)

DOWN SYNDROME

Canadian Down Syndrome
Society (CDSS)
811-14 St. NW
Calgary, AB
Canada T2N 2A4
(800) 883-5608 (Toll Free) in
Canada only
(403) 270-8291 (phone/fax)
✉dsinfo@cdss.ca
http://www.cdss.ca

Down Syndrome Research
Foundation
3580 Slocan St.
Vancouver, BC
Canada V5M 3E8
(604) 431-9694
(888) 464-3773 (Toll Free in BC)
(604) 431-9248 (fax)
✉info@dsrf.org

The London Down Syndrome
Association
Kevin Henderson, President
31 Chaucer Ct.
London, ON
Canada N6K 1V1
(519) 472-0119
✉ldsa@hotmail.com
http://www.geocities.com/ldsa_ca

Manitoba Down
Syndrome Society
825 Sherbrook St.
Winnipeg, MB
Canada R3A 1M5
(204) 992-2731
(204) 975-3027 (fax)
✉mdss@mts.net

Up About Down
2091 W. Grand Ct.
Windsor, ON
Canada N9E 1G7
(519) 972-5835
(519) 972-5835 (fax)
✉upabout_down@excite.com

DYSTONIA

Dystonia Information Centre
Katie Dycke
201-555 Ellice Ave
Winnipeg MB Canada R3B 3C4
(204) 772-1411

Tri-County Dystonia
Support Group
RR#7
Dresden, ON
Canada N0P 1M0
(519) 354-6833
(519) 354-3617 (fax)

EPILEPSY

Cochrame Temiskaming
Epilepsy Association
Rhonda Latendresse
273 Thrid Ave #203
Timmins On Canada P4N 1E2
(705) 264-2933
(705) 264-0350 (fax)
✉ctea@volnetmmp.net

Epilepsy-Durham Region
Ste 200-209 Dundas St. E.
Whitby, ON
Canada L1N 7H8
(905) 666-9926
(905) 666-4529 (fax)
✉edr@durham.net

Epilepsy Ontario
Ste. 308, 1 Promenade Circle
Thornhill, ON
Canada L4J 4P8
(905) 764-5099
(905) 764-1231 (fax)
✉info@epilepsyontario.org
http://epilepsyontario.org

Southern Alberta
Epilepsy Association
447 Mayor Magrath Drive South
Lethbridge, AB
Canada T1J 3L8
(403) 328-8344
(403) 349-0994 (fax)
✉epilepsy@telusplanet.net

FETAL ALCOHOL SYNDROME

FAS/FAE Information Service -
National Bilingual Service
75 Albert St., Ste. 300
Ottawa, ON
Canada K1P 5E7
(613) 235-4048
(800) 559-4514
(Toll Free in Canada)
(613) 235-8101 (fax)
✉fas@ccsa.ca

HEARING IMPAIRMENTS

Canadian Hard
of Hearing Association
NF Chapter Parents Group
PO Box 5203
St. John's, NF
Canada A1C 5V5
(709) 753-3224
(709) 753-5640 (fax)
✉chha-nc@nfld.com
http://www.chha-nc.nf.ca

BC Family Hearing
Resource Centre
8-15355-102A Ave.
Surrey, BC
Canada V3R 7K1
(604) 584-2827
(604) 584-9108 (TTY)
(604) 584-2800 (fax)
✉elks@uniserve.com

Canadian Deaf
Blind& Rubellla Association
Dr. Linda Mamer
350 Brant Ave
Brantfnd, ON Canada N3T 3J9
(604) 668-6579
(604) 668-7812 (FAX)
✉lmamer@compuservice.com

Island Deaf and Hard
of Hearing Centre (IDHHC)
300-1627 Fort St.
Victoria, BC Canada V8R 1H8
(250) 592-8144
(250) 592-8147 (TDD)
(250) 592-8199 (fax)
✉idhhc@tnet.net
http://www.com/~idhhc/

Island Deaf and Hard of Hearing
Centre (IDHHC)
205-55 Victoria Rd.
Nanaimo, BC
Canada V9R 5N9
✉iddhc@island.net
http://www.com/~idhhc/

Manitoba School for the Deaf
242 Stradford St.
Winnipeg, MB
Canada R2Y 2C9
(204) 945-8934
(204) 945-1767 (fax)

Speech, Language & Hearing
Association of Alberta (SHAA)
Ste. 33, 10215-178 Street
Edmonton, AB
Canada T5S 1M3
(780) 944-1609
(780) 408-3925 (fax)
✉headoffice@shaa.ab.ca
http://www.shaa.ab.ca

Voice for Hearing
Impaired Children
161 Eglinton Ave. E.,
Ste. 701
Toronto, ON
Canada M4P 1J5
(416) 487-7719
(416) 487-7423 (fax)
✉voice@web.net

HUNTINGTON'S DISEASE

Huntington Society
Medical Genetics,
Royal Univ. Hospital
Saskatoon, SK
Canada S7N 0W8
(306) 373-6723
(306) 655-1736 (fax)

HYDROCEPHALUS

(see spina bifida)

INCONTINENCE

The Canadian Continence
Foundation
PO Box 30
Westmount, QC
Canada H3Z 2V4
(514) 488-8379
(514) 488-1379 (fax)
✉help@continence-fdn.ca

HYPERLEXIA

Canadian Hyperlexia Association
Robin Leszner
300 John St #87673
Thornhill , ON Canada L3T 7B3
(905) 886-9163
(905) 886-4624 (FAX)
✉cha@ican.net

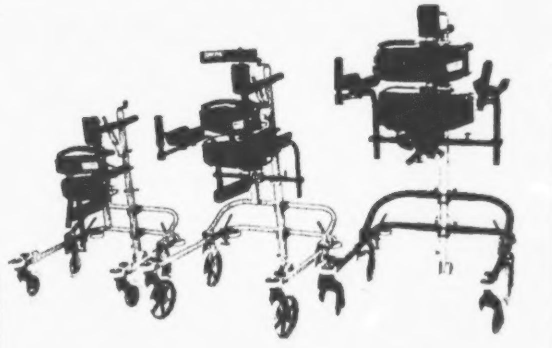
LEARNING DISABILITIES

Learning Disabilties
Association of Canada
323 Chapel St., Ste. 200
Ottawa, ON Canada K1M 7Z2
(613) 238-5721
(613) 235-5391 (fax)
✉information@ldac-taac.ca
http://www.ldac-taac.ca

The Learning Disabilities
Association of BC
Surrey Chapter
205-13766-72nd Ave.
Surrey, BC
Canada V3W 2P4
(604) 591-5156
(604) 591-1669 (fax)

continued on page 182

The New WALKABOUT MODEL 'C'



The new WALKABOUT MODEL 'C' offers 15 lb. babies to 190 lb. adults, who cannot fully weight -bear and walk, the exciting opportunity of learning and strengthening normal gait patterns and their associated muscle groups.

The WALKABOUT MODEL 'C' Features:

- Posterior, hands-free support.
- Crank adjustable height and weight relief.
- Wide ranges of adjustability, including: height, width, angle, gravity assist, and frame length.
- Newly designed accessories.
- No environmental restrictions; the user's environment is reachable

Mulholland
Positioning Systems Inc.

Rep. territories open

PO Box 391 - 215 N. 12th St., Santa Paula, CA 93061 · 800/543-4769 · fax: 805/933-1082 · www.mulhollandinc.com

Circle #94 or visit www.eparent.com/adinfo

CHILEDA INSTITUTE

Educators for youth with developmental disabilities. Residential treatment center provides complete training & intensive therapy for children with severe mental & physical disabilities, closed head injuries & challenging behaviors. Founded 1973.

- Intensive
- Progressive
- Specialized

founded in 1973

Chileda Institute

1020 Mississippi Street • La Crosse, WI 54601
608-782-6480 • Fax: 608-782-6482
Web site: www.chileda.org

Circle #39 or visit www.eparent.com/adinfo

MULTICHAIR 4000

- The multichair 4000 has all the features needed in a roll-in shower/toilet chair plus our unique clamping system makes the chair both strong and stable for everyday use and **light weight and portable** for travel.
- Constructed of aluminum, plastic and stainless steel which won't rust or corrode.
- Revolutionary drop rail provides 5"of clear front or side access.
- Laboratory tested to support up to 350 lbs. yet weighs only 25lbs.
- We have a V.A. contract: # V797P-3846K.

nuprodx,inc. **www.nuprodx.com (888) 288-5653**

Circle #99 or visit www.eparent.com/adinfo

CANADIAN RESOURCES

continued from page 180

The Learning Disabilities Association of BC
Vancouver Chapter
3rd Fl., 210 W. Broadway
Vancouver, BC
Canada V5Y 3W2
(604) 873-8139
(604) 873-8140 (fax)
✉LDA-Van@telus.net

The Learning Disabilities Association of BC
Vernon Chapter
204-3402-27th Ave.
Vernon, BC
Canada V1T 1S1
(250) 542-5033
(250) 542-5033 (fax)
✉lda-vernonbc@home.com

The Learning Disabilities Association of Halton
Ste. 203, 323 Kerr St.
Oakville, ON
Canada L6K 3B6
(905) 844-6905
(905) 844-9529 (fax)

The Learning Disabilties Association of London-Middlesex - Chapter of LDA Ontario
171 Queens Ave., #305
London, ON
Canada N6A 5J7
(519) 438-6213
(519) 438-0368 (fax)

Learning Disabilties Association of New Brunswick
Provincial Office
100A-403 Rue Regent
St. Fredericton, NB
Canada E3B 3X6
(506) 459-7852
(877) 544-7852 (Toll Free NB)
(506) 455-9300 (FAX)
✉ldanb@naid.ca
http://www.naid.ca/ldanb.htm

The Learning Disabilities Association of North York & Toronto
121 Willowdale Ave., Ste. 203
Toronto, ON
Canada M2N 6A3
(416) 229-1680
(416) 229-1681 (fax)
✉admin@ldany.on.ca

Prince George Dyslexic Support Society Learning Difficulties Centre Of Northen BC
Tracey J. Harrison
144 George St
Prince George BC Canada V2L 1P9
(250) 564-8011
(250) 564-8055 (fax)
✉ldx@paralyax.com

LUPUS

Lupus Foundation of Ontario
294 Ridge Rd. N.
PO Box 687
Ridgeway, ON
Canada L0S 1N0
(905) 894-4611
(905) 894-4616 (fax)
✉lupusont@uaxxine.com
http://www.uaxxine.com/lupus

Lupus Society of Alberta
200, 1301-8 St. SW
Calgary, AB
Canada T2R 1B7
(403) 228-7956
(403) 228-7853 (fax)
✉lupuslsa@home.com

MENTAL HEALTH

ARA Mental Health Action Research & Advocacy Assn. of Greater Vancouver
421-119 W. Pender St.
Vancouver, BC
Canada V6B 1S5
(604) 689-7938
(604) 689-7318 (fax)

Canadian Mental Health Association
67 King St. E.
Kitchener, ON
Canada N2G 2K4
(519) 744-7645 ext.228
(519) 744-7060 (fax)
✉toopee@cmhawrb.on.ca

Canadian Mental Health Association Grey Bruce Branch
1024 2nd Ave. E
Owen Sound, ON
Canada N4K 2H7
(519) 371-3642
(519) 371-6485 (fax)
✉cmhagb@bmts.com

Canadian Mental Health Association Pictou County Branch
PO Box 959
New Glasgow, NS
Canada B2H 5K7
(902) 755-9441

Canadian Mental Health Association Prince George Branch
555 George St.
Prince George, BC
Canada V2L 1R8
(250) 564-8644
(250) 564-6155 (fax)
✉cmhapg@netbistro.com

Canadian Mental Health Association Timiskaming Branch
36 Prospect Ave.
Kirkland Lake, ON
Canada P2N 2V4
(705) 567-9596
(705) 567-5211 (fax)
✉cmhatmsk@nt.net

Consumer Survivor Alliance of Windsor and Essex Counties
711 Pellisier St., Unit #3
Windsor, ON
Canada N9A 4L4
(519) 256-4854
(519) 256-3431 (fax)
✉csaw@sprint.ca

Eastern Ontario Council on Mental Health & Deafness
383 Montfort St.
Vanier, ON Canada K1L 5M9
(613) 748-3057
(613) 748-9610 (fax)
✉eocmhd.rene@sympatico.ca

L'Accolade Chateauguay
12-127 St. Jean Baptiste
Chateauguay, QC
Canada J6K 3B1
(450) 699-7059
(450) 699-1562 (fax)
✉laccolade@qc.aura.com

MOOD DISORDERS

Mood Disorders Association of MB
49 Main St.
Flin Flon, MB
Canada R8A 1S1
(204) 687-5811
(204) 687-6015 (fax)

Mood Disorders Association of MB
245 2nd Ave . W
The Pas, MB
Canada R9A 1F4
(204) 623-7437
(204) 623-4254 (fax)
✉nsdmdm2@mb.sympatico.ca

MULTIPLE SCLEROSIS

Multiple Sclerosis Society of Canada
Thunder Bay Chapter
Ste. 102-79 N. Court St.
Thunder Bay, ON
Canada P7A 4T7
(807) 344-2944
(807) 346-5923 (fax)
✉mssoctb@norlink.net

NEUROFIBROMATOSIS

Neurofibromatosis Association of Saskatchewan, Inc.
450 Kirkpatrick Ct.
Saskatoon, SK
Canada S7l 6Z3
(306) 384-3540

NEUROLOGICAL IMPAIRMENTS

Association for the Neurologically Disabled of Canada
59 Clement Rd.
Etobicoke, ON
Canada M9R 1Y5
(416) 244-1992
(416) 244-4099 (fax)
✉info@And.ca

RARE DISORDERS

Canadian Organization for Rare Disorders
2303-20 St.
Coaldale, AB
Canada T1M 1G5
(403) 345-4544
(403) 345-3948 (fax)

REFLEX SYMPATHETIC DYSTROPHY

Canadian RSD Network
107-60 Anderton Ave.
Courtenay, BC
Canada Y9N 2G8
(250) 338-5835
(250) 338-5835 (fax)
✉info@canadianrsd.com

SCHIZOPHRENIA

Schizophrenia Society Of New Brunswick Saint John Chapter (SSNB-SJ)
Kimberly Charlton
P.O Box 20062
Saint John, NB Canada E2L 5B2
(506) 649-2705
(506) 649-2686 (Fax)

SICKLE CELL DISEASE

The Sickle Cell Association of Ontario
3199 Bathurst St., Ste. 202
Toronto, ON
Canada M6A 2B2
(416) 789-2855
(416) 789-1903 (fax)
✉sicklecell@look.ca

SPEECH DISORDERS

London Speech & Language Centre
1589 Fanshawe Park Rd.
London, ON
Canada N5X 3Z9
(519) 642-7270
(519) 642-2470 (fax)
✉speech@on.aibn.com

Speak Easy, Inc.
95 Evergreen Ave.
St. John, NB
Canada E2N 1H4
(800) 345-9022
(800) 345-9022 (fax)
✉info@speakeasycanada.com
(Deals with Stuttering)

Speechmasters of Ottawa
29 Brent Ave.
Ottawa Province, ON
Canada K2G 3L1
(613) 226-7001
✉normdee@home.com

SPINA BIFIDA

Spina Bifida and Hydrocephalus Association of Canada
Andrea Salmon, Executive Director
167-167 Lombard Ave.
Winnipeg, MB
Canada R3B 0T6
(204) 925-3650
(204) 925-3654 (fax)

Spina Bifida and Hydrocephalus Association of Northern Alberta
5R Wing, Edmonton General
11111 Jasper Ave.
Edmonton, AB
Canada T5K 6L4
(780) 482-8281
(780) 482-8964 (fax)
✉sbhana@telusplanet.net

Spina Bifida and Hydrocephalus Association of Ontario
69 Yonge St., Ste. 500
Toronto, ON
Canada M5E 1K3
(416) 214-1056
(416) 214-1446 (fax)
✉provincial@sbhao.on.ca

Windsor District Chapter Spina Bifida and Hydrocephalus Association of Ontario
Barbara Vandelinder
Ste. E, 1168 Drouillard Rd.
Windsor, ON
Canada N8Y 2R1
(519) 252-0732
(519) 252-0913 (fax)
✉sbhaowindson@hotmail.com

SPINAL CORD INJURIES

The Anne Johnston Health Station
2398 Yonge St.
Toronto, ON
Canada M4P 2H4
(416) 486-8666
(416) 486-8660 (fax)
✉ajhs@pathcom.com

STROKE

Stroke Recovery Association of Ontario
80 Bradford St., Unit 239A
Barrie, ON
Canada L4N 6S7
(888) 540-6666 (Toll Free)
(705) 737-9549
(705) 737-9982 (fax)
✉srao@mcw.net

STUTTERING

Association Des Jeunes Beguse Du Quebec
Patrica Vincent
230 Road Heari-Bourassa GST.
buc 315
Montreal, QC Canada H3L 1B8
(514) 388-8455
(514) 388-8422 (FAX)
✉info@ajbq.qc.ca

TOURETTE SYNDROME

Tourette Syndrome Foundation of Canada-London Chapter
Box 28084
London, ON
Canada N6H 5E1
(519) 457-4586
✉rayrobertson@hotmail.com

VISUAL IMPAIRMENTS

Audio Vision Canada
150 Laird Dr.
Toronto, ON
Canada M4G 3V7
(416) 422-4989x238
(416) 422-4847 (fax)
✉nbrs@idirect.com

Canadian National Institute for the Blind
4-2350 Labieux Rd.
Nanaimo, BC
Canada V9T 3M6
(250) 751-2342
(250) 751-2339 (fax)
✉glemnita@bc.cnib.ca
http://www.cnib.ca

Canadian National Institute for the Blind
1929 Bayview Ave.
Toronto, ON
Canada M4G 3E8
(416) 480-7209
(416) 480-7453 (fax)
✉goldd@cnib.ca

Canadian National Institute for the Blind
4920-47 St., Box 872
Yellowknife, NT
Canada X1A 2N6
(867) 873-2647
(867) 873-0289 (fax)
✉cvernon@ab.cnib.ca

Montreal Association for the Blind-EIB
7000 Sherbrooke St. W.
Montreal, QC
Canada H4B 1R3
(514) 489-8201 (local-1052)
(514) 489-9491 (fax)

Canadian Deafblind and Rubella Association (CDBRA)
83 Tucker Crescent
Saskatoon, SK
Canada S7H 3H7
(306) 374-0022
(306) 374-0004 (fax)

Institut Nazareth et Louis-Braille
4111 St. Charles St West Tower
2nd Floor
Longvevil, QC
Canada J4K 5G4
(450) 463-1710 x246
(450) 463-0243 (fax)
✉rsenecal@inlb.qc.ca

Visual Groundwork
398 O'Connor St., Ste. 209
Ottawa, ON
Canada K2P 1W3
(613) 565-7463 (fax)
✉visionconsult@Canada.com

TRAVEL

London Community Transportation Brokerage
450 Highbury Ave.
N. London, ON
Canada N5W 5L2
(519) 451-1340 ext.366
(519) 451-4411 (fax)

PRODUCT & SERVICES DIRECTORY

ADA INFORMATION, CAREER PLANNING

Litigators Incorporated, Inc.
& Affiliated Law Firms
Attorneys Across The Nation
CP & Brain Damage
Toll Free: (800) 529-3350
E-mail: litigatorsinc@msn.com
www.thelitigatorsinc.com
Circle # 84
See our ad on page 118

AQUATICS

Aquatic Access Inc.
P: 800-325-LIFT
F: 502-425-9607
www.AquaticAccess.com
Manufactures and sells water-powered lifts providing access to swimming pools, spas, boats and docks. Custom work also available

Sure Hands Lift & Care Systems
982 Route 1
Pine Island, NY 10969
P: (800) 724-5305
F: (845) 258-6634
email: info@surehands.com
www.surehands.com
Circle # 123
See our ad on page 148

ASSISTIVE TECHNOLOGY

AbleNet, Inc.
1081 Tenth Avenue SE
Minneapolis, MN 55414-1312
P: 612-379-0956 or 800-322-0956
F: 612-379-9143
www.ablenetinc.com
AbleNet designs and markets assistive technology products and services that empower people with severe and profound disabilities to learn, participate and communicate in daily activities at home, school, work and in the community. We also develops workshops, seminars, written materials, other information that support and assist families, educators, therapists and care providers worldwide.

Advanced Respiratory, Inc.
1020 West County Rd F
St. Paul, MN 55126
P: 1-866-411-VEST
www.thevest.com
Manufacturer of The Vest TM Airway Clearance System, a home-use device utilizing high-frequency chest wall oscillation (HFCWO) to loosen, thin, and clear mucus from airways
Circle # 18
See our ad on page 3

Assistive Technology Program
at Children's Hospital
2924 Brook Road
Richmond, Virginia 23220
P: (804) 228-5818
F: (804) 228-5808
www.childrenshosp-richmond.org
Evaluation and training on daily living aids, communication devices, customized seating, etc.
Circle # 38
See our ad on page 79

DynaVox Systems LLC
2100Wharton St.
Pittsburgh, PA 15203
P: 412-381-4883 F: 412-381-5241
www.dynavoxsys.com
Circle # 54
See our ad on page 44

Matheny School and Hospital
P.O. Box 339, Main Street
Peapack, NJ 07977
P: (908) 234-0011
e-mail: info@matheny .org
www.matheny.org
Circle # 88
See our ad on page 168

Maui Innovative Peripherals
300 Ohukai Road C-325
Kihei, HI 96753
P: (808) 875-0555
F: (808) 875-8775
www.maui-innovative.com
Circle # 89
See our ad on page 179

Pathways Development Group, Inc.
17409 - 57th Avenue West
Lynnwood, WA 98037
P: 1(877) 742-4604
F: (425) 745-9279
www.pathwaysdg.com
Circle # 104
See our ad on page 191

Sammons Preston
4 Sammons Court
Bolingbrook, IL 60440
P: 800-323-5547
F: 800-547-4337
email: sp@sammonspreston.com
www.sammonspreston.com
Circle # 114
See our ad on page 46

TFH (USA)
4537 Gibsonia Road
Gibsonia, PA 15044
P: 800-467-6222
F: 724-444-6411
www.TTFHUSA.com
info@tfhusa.com
Adopted toys and products for children with special needs. Create a multi-sensory environment in your child's bedroom with "vista"

Vcom3D, Inc.
3452 Lake Lynda Drive, Suite 260
Orlando, FL 32817
P: (407)737-7310 x111
F: (407)737-6821
e-mail: signingavator.com
www.signingavatar.com

BigKeys Keyboard
P.O. Box 1888
Huntersville NC 28078
P: (800) 249-5397
F: (704) 875-8936
www.bigkeys.com
The new BigKeys LX: a standard-size keyboard with oversize keys all the function & punctuation keys you need. One-inch square keys. Easy to See & Easy to Use. QWERTY or ABC key order. No special software required.
Circle # 65
See our ad on page 175

FlagHouse
601 FlagHouse Drive
Hasbrouck Heights, NJ 07604-3116
P: (800) 793-7900
F: (800) 793-7922
e-mail: sales@flaghouse.com
www.flaghouse.com
Circle # 57
See our ad on page 1

Ultraflex Systems Inc.
534 Trestle Place
Trestle Bridge Business Center
Downingtown, PA 19335-3459
P: 610-269-5880
F: 610-269-5909
www.ultraflexsystems.com
FirstFlex(is a breakthrough treatment for children with upper extremity Cerebral Palsy induced spastic hemiplegia.
Circle # 132
See our ad on page 78

Verizon Center for
Customers with Disabilities
280 Locke Drive
Marlboro, MA 01752
P: (800) 974-6006 (V/TTY)
www.verizon.com
Circle # 134
See our ad on page 45

AUGMENTATIVE COMMUNICATIONS EQUIPMENT

AbleNet, Inc.
1081 Tenth Avenue SE
Minneapolis, MN 55414-1312
P: 612-379-0956 or 800-322-0956
F: 612-379-9143
www.ablenetinc.com
AbleNet designs and markets assistive technology products and services that empower people with severe and profound disabilities to learn, participate and communicate in daily activities at home, school, work and in the community. We also develops workshops, seminars, written materials, other information that support and assist families, educators, therapists and care providers worldwide.

Wizcom Technologies, Inc.
257 Great Road
Acton, MA 01720
P: (978) 635-5357
F:(978) 263-6565
www.wizcomtech.com
Circle # 139
See our ad on page 122

Ability Research, Inc
PO Box 1721
Minnetonka, MN 55345
952-939-0121 Fax: 952-890-8393
www.abilityresearch.com
Innovative and affordable communication products such as the Hand Held Voice portable dynamic screen communicator.

DynaVox Systems LLC
2100Wharton St.
Pittsburgh, PA 15203
P: 412-381-4883 F: 412-381-5241
www.dynavoxsys.com
Circle # 54
See our ad on page 44

Tykris Inc.
PO Box 309
3272 15 Side Road
Campbellville, ON L0P 1B0
P: 905-854-3009
F: 905-854-3012
e-mail: tykris@tykris.com
www.tykris.com

AUGMENTATIVE EVALUATION

DynaVox Systems LLC
2100Wharton St.
Pittsburgh, PA 15203
P: 412-381-4883 F: 412-381-5241
www.dynavoxsys.com
Circle # 54
See our ad on page 44

BATHROOM EQUIPMENT

Columbia Medical Mfg. Corp.
PO Box 633
Pacific Palisades, CA 90272
P: (800) 454-6612
F: (310) 305-1718
www.columbiamedical.com
Circle # 41
See our ad on page 20

Duralife, Inc.
195 Phillips Park Drive
S. Williamsport, PA 17702
P: (570) 323-9743
F: (570) 323-9762
www.duralife-usa.com
Circle # 52
See our ad on page 176

Guldmann Inc.
5505 Johns Road, Suite 700
Tampa, FL 33634
P: 800 664-8834
F: 813 880-9558
www.guldmann.com
e-mail: info@guldmann.net
Circle # 66
See our ad on page 146

Medi-Fair, Inc.
25 Jefferson Street
Monticello, NY 12701
P: (800) 282-6334 or (845) 342-3003
F: (845) 794-0712
www.medifair.com
Circle # 90
See our ad on page 177

Nuprodx, Inc.
461 Second Street
San Francisco, CA 94107
P: (415) 243-0923
F: (415) 957-1050
http://www.nuprodx.com
Circle # 99
See our ad on page 181

Sage Products, Inc.
3909 Three Oaks Road, Cary, IL 60013
P: (800) 323-2220
F: (815) 455-5599
e-mail: customerservice@sageproducts.com
www.comfortbath.com
Circle # 113
See our ad on page 153

Sammons Preston
4 Sammons Court
Bolingbrook, IL 60440
P: 800-323-5547
F: 800-547-4337
email: sp@sammonspreston.com
www.sammonspreston.com
Circle # 114
See our ad on page 46

Sure Hands Lift & Care Systems
982 Route 1
Pine Island, NY 10969
P: (800) 724-5305
F: (845) 258-6634
email: info@surehands.com
www.surehands.com
Circle # 123
See our ad on page 148

BEDDING

Bodypoint Design, Inc.
558 First Avenue South Suite 300
Seattle, WA 98104
P: (800) 547-5716
F: (206) 405-4556
www.bodypoint.com
Circle # 32, 33, 34
See our ad on page 99, 148, 175

Hertz Supply CO. Inc.
4670 Schantz Rd. Ste A
Allentown, PA 18104
P: 800-321-4240
F: 610-366-1808
www.hertzsupply.com
Circle # 72
See our ad on page 177

Vail Products, Inc.
235 First Street
Toledo, OH 43605
P: 800-235-8245
F: 419-698-1174
email: vailbed@vailbed.com
www.vailbed.com
Special needs patients require special supervision. But one-on-one care can sap the resources of the most dedicated caregiver. Seizures. Head-banging. Falls from bed. Wandering. They take their toll on a night's sleep—for the patient and the caregiver. A Vail Enclosed Bed System may be the answer.
Circle # 133
See our ad on page C4

Vivax Medical Corporation
89 Putter Lane
Torrington, CT 06790
P: (860) 489-7890
F: (860) 489-7935
www.vivaxmedical.com
Our Soma Safe enclosure provides safety, comfort, and a sense of security.

BICYCLES

Cycletote, Inc.
517 North Link Lane
Fort Collins, CO 80524
P: (800) 747-2407
F: (970) 482-2402
http://www.cycletote.com
See our ad on page 167

Freedom Concepts Inc.
"Making Mobility A Reality"
P.O. Box 45117 RPO Regent
Winnipeg, Manitoba R2C 5C7
P: 800-661-9915 or 204-654-1074
F: 204-654-1149
email: mobility@freedomconcepts.com
www.freedomconcepts.com
Circle # 59
See our ad on page 115

Haverich Ortho-Sport, Inc.
165 Martell Court
Keene, NH 03431
P: (603) 358-0438 or (800) 529-9444
F: (603) 358-0438
www.haverich.com
Circle # 71
See our ad on page 107

CLOTHES, SPECIAL & FOOTWEAR

Able Apparel
2121 Hillside Avenue
New Hyde Park, NY 11040
P: (516) 873-6552
F: (516) 248-7308
www.ableapparel.com

M.J. Markell Shoe Company
504 Saw Mill River Road
Yonkers, New York 10702
P: (914) 963-2258
F: (914) 963-9293
e-mail: info@markellshoe.com
http://www.markellshoe.com
Superior quality foot products
Circle # 85
See our ad on page 88

Special Clothes
P. O. Box 333
East Harwich, MA 02645
P: (508) 896-7939
F: (508) 896-7939
e-mail: specialclo@aol.com
www.SPECIAL-CLOTHES

DRIVING AIDS

Mobility Solutions Inc.
840 Cumberland Hill Road
Woonsocket, RI 02895
P: (401) 766-7000 or (866) 766-7001
F: (401) 766-4000
www.mobilitysolutionsonline.com

Information and support for the special needs community

PARENTS ○ FAMILIES ○ PHYSICIANS ○ PROFESSIONALS

EP

SYMBOL OF EXCELLENCE · CONTENT · COMMUNITY · CARE

Exceptional Parent Magazine

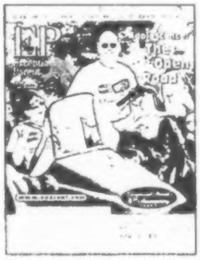
Welcome Resources Technology Edu/Toys Healthcare Subscribe

eparent.com

New! Visit the EP Web site, EParent.com, and discover...

EP
Exceptional
Parent

BOBBY APPROVED
Click here for our Text only site.

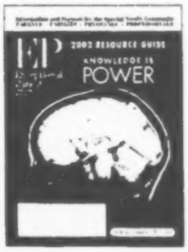


TOYS—The new eToys Web site (www.etoys.com) teams with EP's Web site, EParent.com (www.eparent.com) to offer ideas, information and imaginative toys for families with kids who have special needs. When parents, teachers or caregivers shop at eToys and visit the co-branded EParent.com site, they'll find hand picked toys and games, plus featured articles from EP Magazine. The site also features direct links to the EParent.com shop at eToys, and eToys products recommended by experts or reviewed by organizations chosen by EP Magazine.

EDUCATION—EParent.com's newly-constructed Education channel (EDU/TOYS tab) yields a wealth of current articles on topics such as IDEA, IEPs, assistive technology, transitioning and inclusion. These are supplemented by a growing directory of schools, camps & residences, which can be found in the "Directories" link of the "Resources" channel.

NOW SUBSCRIBE ON-LINE

ON-LINE ARCHIVES—Now, EParent.com users can preform keyword searches through our on-line archives and purchase articles which have appeared, as far back as in the eighties, in EP Magazine (recipient of awards from Folio:The Magazine for Magazine Management, Easter Seals, Consumer Healthcare Group). These include classic pieces on such subjects as early childhood, rare disorders, technology, education, medical research update, transitioning, travel, all of which have distinguished EP Magazine through the years.



MORE TO COME IN 2002—You can also click through our EP Library (www.eplibrary.com) which contains books, videos and software encompassing almost 50 specific and general categories, with more than 650 titles. Of course, we will continue to refresh and improve EParent.com in 2002, and look forward to receiving your comments and suggestions. Log on and find out what we are all about!

National Resource Directory

www.eparent.com

WWW.EPLIBRARY.COM
EP LIBRARY
THE SPECIAL NEEDS BOOKSTORE

BEST COPY AVAILABLE

PRODUCT & SERVICES DIRECTORY

Ride-Away Corp.
51 Wentworth Avenue
Londonderry, NH 03053
P: (888) Ride-Away
F: (603) 432-1549
www.ride-away.com
Other locations include N. Attleboro, MA, E. Hartford, CT and Essex Junction, VT

EDUCATIONAL MATERIAL

American Printing House for the Blind
1839 Frankfort Avenue
Louisville, KY 40206
P: 502-895-2405
F: 502-899-2274
www.aph.org
Circle # 21
See our ad on page 192

Different Roads to Learning
12 West 18th Street 3 East
New York, NY 10011
P: (800) 853-1057
F: (212) 206-9329
www.difflearn.com
A Catalog of ABA Learning Materials for Children Diagnosed with Autism

Litigators Incorporated, Inc.
& Affiliated Law Firms
Attorneys Across The Nation
CP & Brain Damage
Toll Free: (800) 529-3350
E-mail: litigatorsinc@msn.com
www.thelitigatorsinc.com
Circle # 84
See our ad on page 118

Maddak Inc.
6 Industrial Road
Pequannock, NJ 07440
P: (973) 628-7600
F: (973) 305-0841
www.maddak.com
Circle # 86
See our ad on page 179

Pathways Awareness Foundation
P: 800-955-2445
F: 888-795-5884
TTY: 800-326-8154
e-mail:
friends@pathwaysawareness.org
www.pathwaysawareness.org
Circle # 103
See our ad on page 68

Athena Diagnostics
Four Biotech Park
377 Plantation Street
Worcester, MA 01605
P: 800-394-4493
F: 508-753-5601
www.athenadiagnostics.com
Circle # 25
See our ad on page 21

Vcom3D, Inc.
3452 Lake Lynda Drive, Suite 260
Orlando, FL 32817
P: (407)737-7310 x111
F: (407)737-6821
e-mail: signingavator.com
www.signingavatar.com

ENVIRONMENTAL CONTROLS

AbleNet, Inc.
1081 Tenth Avenue SE
Minneapolis, MN 55414-1312
P: 612-379-0956 or 800-322-0956
F: 612-379-9143
www.ablenetinc.com
AbleNet designs and markets assistive technology products and services that empower people with severe and profound disabilities to learn, participate and communicate in daily activities at home, school, work and in the community. We also develops workshops, seminars, written materials, other information that support and assist families, educators, therapists and care providers worldwide.

FINANCE/ESTATE PLANNING/INSURANCE

Litigators Incorporated, Inc.
& Affiliated Law Firms
Attorneys Across The Nation
CP & Brain Damage
Toll Free: (800) 529-3350
E-mail: litigatorsinc@msn.com
www.thelitigatorsinc.com
Circle # 84
See our ad on page 118

Special Needs Advocate for Parents (SNAP)
1801 Avenue of the Stars #401
Los Angeles, CA 90067
P: (888) 310-9889
F: (310)-201-9889
www. snapinfo.org
Circle # 117
See our ad on page 197

FOOD & NUTRITION

Independent-ADL.Com Dinnerware
1278 Glenneyre St., # N
Laguna Beach, CA 92651
P: (877) 367-2923
F: (949) 464-0341
www.i-adl.com
Circle # 76
See our ad on page 107

International Nutrition & Compounding Pharmacy
11436 Cronridge Drive, Suite W
Owing Mills, MD 21117
P: 800-899-3413
F: 866-902-1767
e-mail: ask@nutrivene.com
www.nutrivene.com
Specialize in nutrition supplements and compounded drugs and medications for children and adults with special needs — including Down syndrome, ADD/ADHD, CP, autism, etc. Can customize supplements and medications for individual needs.

Pediatric Feeding Disorders
Program at Children's Hospital
2924 Brook Road
Richmond, Virginia 23220
P: (804) 228-5818
F: (804) 228-5808
www.childrenshosp-richmond.org
Interdisciplinary team approach combines medical, behavioral and oral-motor treatments for medically-based feeding disorders.
Circle # 38
See our ad on page 79

Precision Foods
4317 Val DeChiana Ave.
Las Vegas, NV 89141
P: 1-800-333-0003
F: 1-702-269-8109
www.precisionfoods.com
Precision Foods manufactures Thick-It, an instant food thickener designed to assist people with swallowing disorders. It quickly and easily mixes into hot and cold liquids without lumping or over-thickening. Thick-It also thickens pureed foods. Use Thick-It to mix foods and beverages to any consistency. It imparts no odor, flavor or color to the food or beverage it is thickening.
Circle # 107
See our ad on page 93

SHS North America
P.O. Box 117
Gaithersburg, MD 20884
P: 800-365-7354
F: 301-795-2301
www.shsna.com
SHS North America, World Specialist in Clinical Nutrition, offers a wide range of specialized products for the management of conditions that benefit from nutritional therapy. Please contact us for information about our following product ranges: Hypoallergenic/GI, Neurology, and Inborn Errors of Metabolism. Neocate®, KetoCal®, and the Phlexy-10® system are just a few of our key products.
Circle # 115
See our ad on page 11

FURNITURE

Bodypoint Design, Inc.
558 First Avenue South Suite 300
Seattle, WA 98104
P: (800) 547-5716
F: (206) 405-4556
www.bodypoint.com
Circle # 32, 33, 34
See our ad on page 99, 148, 175

R.E.A.L. Design Inc.
187 South Main St.
Dolgeville, NY 13329
P: (800) 696-7041
F: (315) 429-3071
www.realdesigninc.com
Circle # 110
See our ad on page 195

HEADGEAR

Verizon Center for Customers with Disabilities
280 Locke Drive
Marlboro, MA 01752
P: (800) 974-6006 (V/TTY)
www.verizon.com
Circle # 134
See our ad on page 45

HOBBIES & TOYS

BigKeys Keyboard
P.O. Box 1888
Huntersville NC 28078
P: (800) 249-5397
F: (704) 875-8936
www.bigkeys.com
The new BigKeys LX: a standard-size keyboard with oversize keys all the function & punctuation keys you need. One-inch square keys. Easy to See & Easy to Use. QWERTY or ABC key order. No special software required.
Circle # 65
See our ad on page 175

Pathways Development Group, Inc.
17409 - 57th Avenue West
Lynnwood, WA 98037
P: 1(877) 742-4604
F: (425) 745-9279
www.pathwaysdg.com
Circle # 104
See our ad on page 191

TFH (USA)
4537 Gibsonia Road
Gibsonia, PA 15044
P: 800-467-6222
F: 724-444-6411
www.TTFHUSA.com
info@tfhusa.com
Adopted toys and products for children with special needs. Create a multi-sensory environment in your child's bedroom with "vista"

Southpaw Enterprises, Inc.
P.O. Box 1047
Dayton, OH 45401
P: 1-800-228-1698
F: 937-252-8502
www.southpawenterprises.com
Sensory integration and developmental products.
Circle # 119
See our ad on page 170

HOME ADAPTION/DESIGN

Hard Manufacturing
230 Grider Street
Buffalo, NY 14215
P: (800) 873-4273
F: (716) 896-2579
www.hardmfg.com
Circle # 69
See our ad on page 16

Verizon Center for Customers with Disabilities
280 Locke Drive
Marlboro, MA 01752
P: (800) 974-6006 (V/TTY)
www.verizon.com
Circle # 134
See our ad on page 45

INCONTINENCE

ARC Home Health Products
101 Browne Street
Oneonta, NY 13820
P: (800) 278-8595
F: (607) 433-6745
www.disabilityproducts.com/archhp

Duraline Medical Products, Inc.
324 Werner St. PO Box [illegible]
Leipsic, OH 45856
P: (800) 654-3376
www.dmponline.com
Circle # 53
See our ad on page 148

HDIS (Home Delivery Incontinent Supplies Co., Inc.)
9385 Dielman Industrial Drive
Olivette, MO 63132
P: 1-800-269-4663
F: (314) 997-0047
www.hdis.com
Circle # 67
See our ad on page 168

Principle Business Enterprises, Inc.
P.O. Box 129
Dunbridge, OH 43414-0129
P: 800-467-3224
F: 419-352-1551
e-mail: mifo@gopeach.com
www.gopeach.com
Tranquility & Select Incontinence Products

Sage Products, Inc.
3909 Three Oaks Road, Cary, IL 60013
P: (800) 323-2220
F: (815) 455-5599
e-mail: customerservice@
sageproducts.com
www.comfortbath.com
Circle # 113
See our ad on page 153

Woodbury Products
3580 Oceanside Road
Oceanside, NY 11558
P: (800) 777-1111
F: (516) 594-8315
e-mail: info@woodburycares.com
www.woodburyproducts.com
Circle # 140
See our ad on page 10

MEDICAL EQUIPMENT DEALERS

Advanced Respiratory, Inc.
1020 West County Rd F
St. Paul, MN 55126
P: 1-866-411-VEST
www.thevest.com
Manufacturer of The Vest TM Airway Clearance System, a home-use device utilizing high-frequency chest wall oscillation (HFCWO) to loosen, thin, and clear mucus from airways
Circle # 18
See our ad on page 3

American Discount Medical
11124 NE Halsey # 677
Portland, OR 97220
P: (800) 877-9100
F: (503) 258-8197
e-mail: adm@information4u.com
www.americandiscountmed.com

Connetquot West, Inc.
711-3 Koehler Avenue
Ronkonkoma, NY 11779-7410
P: (800) 719-0711
F: (631) 588-3337
www.connetquot@aol.com
Circle # 42
See our ad on page 196

Medi-Fair, Inc.
25 Jefferson Street
Monticello, NY 12701
P: (800) 282-6334 or (845) 342-3003
F: (845) 794-0712
www.medifair.com
Circle # 90
See our ad on page 177

MOBILITY EQUIPMENT DEALERS

Causeway Ford Lincoln Mercury Jeep
Route 72
Manahawkin, NJ 08050
P: (609) 597-8083
F: (609) 597-2089
www.causewaymobility@yahoo.com
Largest Stocking Mobility Dealer in the State of NJ. Causeway can install your new lift, hand controls or any other piece of mobility equipment.

Liberty Motor Company Inc.
2390 South Service Road West
Oakville, ON L6L 5M9
P: 888-578-8886
F: 905-465-3965
email: sales@libertymotorco.com
www.libertymotorco.com
Circle # 83
See our ad on page 121

Mobility Solutions Inc.
840 Cumberland Hill Road
Woonsocket, RI 02895
P: (401) 766-7000 or (866) 766-7001
F: (401) 766-4000
www.mobilitysolutionsonline.com

Performance Vans/Mobility Services
1549 Gateway Blvd.
Woodbury, NJ 08096
P 800-929-1207
F: 856-853-8341
e-mail: sjvanguy@aol.com
www.performancevan.com

Ride-Away Corp.
51 Wentworth Avenue
Londonderry, NH 03053
P: (888) Ride-Away
F: (603) 432-1549
www.ride-away.com
Other locations include N. Attleboro, MA, E. Hartford, CT and Essex Junction, VT

DIRECTORY OF ADVERTISERS

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in Exceptional Parent.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in Exceptional Parent!

SUBSCRIPTIONS

EXCEPTIONAL PARENT
P.O. BOX 2078,
MARION, OH 43305-2078
(877) 372-7368
New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged.

The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

Circle	Advertiser	Page
17	ABLENET, INC	191
27	ADAPTIVEMALL.COM	146
18	ADVANCED RESPIRATORY	3
19	ALLERGAN	47
20	ALTIMATE MEDICAL	76
21	AMERICAN PRINTING HOUSE F/T BLIND	192
22	ANNANDALE VILLAGE	36
23	ANNE CARLSEN SCHOOL	146
25	ATHENA DIAGNOSTICS INC	21
26	BARRIER FREE LIFTS	74
28	BERKSHIRE MEADOWS	70
29	BETHESDA LUTHERAN	198
30	BEVERLY FARM FOUNDATION	171
31	BIKE-ON.COM	179
32	BODYPOINT DESIGNS, INC	99
33	BODYPOINT DESIGNS, INC	148
34	BODYPOINT DESIGNS, INC	175
36	CHARLES C THOMAS	105
38	CHILDREN'S HOSPITAL	79
39	CHILEDA INSTITUTE	181
40	CNSF	12-13
41	COLUMBIA MEDICAL	20
42	CONNETQUOT WEST	196
43	CONSUMER CARE PRODUCTS, INC	176
44	CONVAID	35
45	CORNELI HEALTHCARE CORP	74
46	CORNELI HEALTHCARE CORP	175
47	COTTING SCHOOL	196
48	CREATIVE PLAY	177
49	CROTCHED MOUNTAIN REHAB	77
50	CRYSTAL SPRINGS SCHOOL	194
51	CYBERONICS, INC	6-7
	CYCLETOTE CORP	167
52	DURALIFE, INC	176
53	DURALINE MEDICAL PRODUCTS	148
54	DYNAVOX SYSTEMS LLC	44
300	EP LIBRARY PAGES	130-131
299	EP SUBSCRIPTION CARD	17-18
55	EQUIPMENT SHOP	189
56	EVERGREEN CENTER	174
57	FLAGHOUSE	1
58	FLORIDA INSTITUTE FOR NEURO/REHAB	106
59	FREEDOM CONCEPTS	115
60	FREEDOM DESIGN	75
61	FREEDOM MOTORS USA	166
	GENERAL MOTORS	43
63	GENZYME/NOVAZYME	2
64	GLOBAL POWER SYSTEMS INC.	107
65	GREYSTONE DIGITAL	175
66	GULDMANN, INC	146
67	H.D.I.S.	168
68	HANDICAPS, INC	174
69	HARD MANUFACTURING	16
70	HARMAR MOBILITY	173
71	HAVERICH ORTHO-SPORT, INC	107
24	HEARTSPRING	89
72	HERTZ SUPPLY CO., INC	177
73	HMS SCHOOL	76
	HOUSE AD	174
74	HOUSE AD	150-151
76	INDEPENDENT-ADL.COM	107
77	INNOVATIVE PRODUCTS	81
78	IRWIN SIEGEL AGENCY	194
79	JUDGE ROTENBERG EDUC. CTR	78
80	KENNEDY KRIEGER	193
81	KIMBERLY CLARK CORP	37
82	LAWYERS, INC	90
83	LIBERTY MOTOR COMPANY INC	121
84	LITIGATORS, INC	118
85	M.J. MARKELL SHOE COMPANY	88
86	MADDAK INC	179
87	MARTHA LLOYD COMMUNITY SERV.	88
88	MATHENY SCHOOL & HOSPITAL	168
89	MAUI INNOVATIVE PERIPHE	179
90	MEDI-FAIR, INC	177
91	MEDTRONIC NEUROLOGICALS, INC	92
92	MELMARK	158
93	MOBILITY RESEARCH	169
94	MULHOLLAND POSITIONING SYS INC	181
95	MULHOLLAND POSITIONING SYS INC	169
97	NATIONAL EASTER SEAL SOCIETY	124
98	NAT'L FAMILY ASSOC. F/T DEAF/BLIND	192
96	NAT'L INSTIT. OF MENTAL HEALTH	176
	NEW ENGLAND VILLAGE	10
99	NUPRODX INC.	181
100	OCEAN HYPERBARIC CENTER	126
101	OTTO BOCK	147
102	PATHFINDER VILLAGE	198
103	PATHWAYS AWARENESS FOUNDATION	68
104	PATHWAYS DEVELOPMENT GROUP INC	191
105	PERKIN ELMER LIFE SCIENCES, INC	149
106	PERMOBIL	19
107	PRECISION FOODS	93
108	PRIDE MOBILITY	101
109	QUESTCOR PHARMACEUTICALS, INC	4
110	REAL DESIGN	195
111	RED BARN ENTERPRISES	88
112	ROSS LABORATORIES	C3
113	SAGE COMFORT BATH	153
114	SAMMONS-PRESTON	46
115	SHS NORTH AMERICA	11
116	SIGMA TAU	C2,119
117	SNAP	197
118	SNUG SEAT INC	5
119	SOUTHPAW ENTERPRISES, INC	170
120	SPORTIME ABILITATIONS	81
121	ST. VINCENT'S SPECIAL NEEDS	199
122	STEWART HOME SCHOOL	122
123	SURE HANDS INTERNATIONAL	148
124	TFH (USA) LTD.	176
125	THE BABY JOGGER COMPANY	74
126	THE CENTER FOR DISCOVERY	91
127	THE NYU HOSP FOR JOINT DIS CTR	15
128	THERADAPT	61
129	THERADYNE HEALTHCARE	125
130	THINKING PUBLICATIONS	189
131	TORONTO HYPERBARIC INC	78
132	ULTRAFLEX SYSTEMS, INC	78
133	VAIL PRODUCTS	C4
134	VERIZON	45
135	VIEWPOINT MOBILITY LLC	76
136	WENZELITE MEDICAL SUPPLY	88
137	WHEELCHAIR GETAWAYS	70
138	WITT/KIEFFER	89
139	WIZCOM TECHNOLOGIES INC	122
140	WOODBURY PRODUCTS	10
141	WORLD CONGRESS	62-65

Exceptional Parent

JANUARY 2002

Free product & service information order card*

FAX this card to 413-637-4343 for quicker response

Please answer the following questions.

A. Are you a subscriber to *Exceptional Parent*?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ____________________

Facility ____________________

Address ____________________

____

City ____________________ State _____ Zip ________

Phone ____________________ Fax ____________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? 1-☐ Yes 2-☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3-☐ Yes 4-☐ No

If Yes, are you a: 5-☐ Physician 6-☐ RN 7-☐ Physical Therapist 8-☐ Occupational Therapist 9-☐ Speech Pathologist; Audiologist 10-☐ Other (please indicate) ____________________

D. Are you an EDUCATOR? 11-☐ Yes 12-☐ No

If Yes, are you a: 13-☐ Special Ed Teacher 14-☐ Regular Ed Teacher 15-☐ Admin/Dir. 16-☐ Other (please indicate) ____________________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? 17-☐ Yes 18-☐ No

If yes, please explain ____________________

____

____

F. Have you ever bought or recommended a product or service you saw advertised in **Exceptional Parent**? 19-☐ Yes 20-☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60
61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100	101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200	201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220	221	222	223	224	225	226	227	228	229	230	231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250	251	252	253	254	255	256	257	258	259	260	261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280	281	282	283	284	285	286	287	288	289	290	291	292	293	294	295	296	297	298	299	300

*CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement.
Expiration date: DECEMBER 31, 2002

BJAN2

Exceptional Parent

JANUARY 2002

Free product & service information order card*

FAX this card to 413-637-4343 for quicker response

Please answer the following questions.

A. Are you a subscriber to *Exceptional Parent*?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ____________________

Facility ____________________

Address ____________________

____

City ____________________ State _____ Zip ________

Phone ____________________ Fax ____________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? 1-☐ Yes 2-☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3-☐ Yes 4-☐ No

If Yes, are you a: 5-☐ Physician 6-☐ RN 7-☐ Physical Therapist 8-☐ Occupational Therapist 9-☐ Speech Pathologist; Audiologist 10-☐ Other (please indicate) ____________________

D. Are you an EDUCATOR? 11-☐ Yes 12-☐ No

If Yes, are you a: 13-☐ Special Ed Teacher 14-☐ Regular Ed Teacher 15-☐ Admin/Dir. 16-☐ Other (please indicate) ____________________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? 17-☐ Yes 18-☐ No

If yes, please explain ____________________

____

____

F. Have you ever bought or recommended a product or service you saw advertised in **Exceptional Parent**? 19-☐ Yes 20-☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60
61	62	63	64.	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90
91	92	93	94	95	96	97	98	99	100	101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120
121	122	123	124	125	126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175	176	177	178	179	180
181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200	201	202	203	204	205	206	207	208	209	210
211	212	213	214	215	216	217	218	219	220	221	222	223	224	225	226	227	228	229	230	231	232	233	234	235	236	237	238	239	240
241	242	243	244	245	246	247	248	249	250	251	252	253	254	255	256	257	258	259	260	261	262	263	264	265	266	267	268	269	270
271	272	273	274	275	276	277	278	279	280	281	282	283	284	285	286	287	288	289	290	291	292	293	294	295	296	297	298	299	300

*CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement.
Expiration date: DECEMBER 31, 2002

BJAN2

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent

PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent

PO BOX 5446
PITTSFIELD MA 01203-9321

PRODUCT & SERVICES DIRECTORY

Vivax Medical Corporation
89 Putter Lane
Torrington, CT 06790
P: (860) 489-7890
F: (860) 489-7935
www.vivaxmedical.com
A Revolutionary New Mobility System that moves a person from bed to chair without a lift.

ORTHEOTICS/PROSTHETICS

Otto Bock Health Care
2 Carlson Parkway North, Suite 100
Minneapolis, MN 55447-4467
P: 763.553.9464
F: 763.519.6153
www.ottobockus.com
Circle # 101
See our ad on page 147

Ultraflex Systems Inc.
534 Trestle Place
Trestle Bridge Business Center
Downingtown, PA 19335-3459
P: 610-269-5880
F: 610-269-5909
www.ultraflexsystems.com
FirstFlex® is a breakthrough treatment for children with upper extremity Cerebral Palsy induced spastic hemiplegia.
Circle # 132
See our ad on page 78

OTHER

Connetquot West, Inc.
711-3 Koehler Avenue
Ronkonkoma, NY 11779-7410
P: (800) 719-0711
F: (631) 588-3337
www.connetquot@aol.com
Circle # 42
See our ad on page 196

Freedom Designs Inc.
2241 Madera Road
Simi Valley, CA 93065
P: (800) 331-8551 or (805) 582-0077
F: (805) 832-1473
Circle # 60
See our ad on page 75

Hard Manufacturing
230 Grider Street
Buffalo, NY 14215
P: (800) 873-4273
F: (716) 896-2579
www.hardmfg.com
Circle # 69
See our ad on page 16

Litigators Incorporated, Inc.
& Affiliated Law Firms
Attorneys Across The Nation
CP & Brain Damage
Toll Free: (800) 529-3350
E-mail: litigatorsinc@msn.com
www.thelitigatorsinc.com
Circle # 84
See our ad on page 118

MOST
P.O. Box 951
Brentwood, NY 11717-0627
P: (631) 859-1110
F: (631) 859-3580
www.mostonline.org

National Family Association for Deaf and Blind (NFADB)
111 Middle Neck Road
Sands Point, NY 11050
P: (800) 255-0411 Ext.275
F: (516) 944-7302
www.nfadb.org
Circle # 98
See our ad on page 192

Questcor Pharmaceuticals, Inc.
3260 Wipple Road
Union City, CA 94587
P: (510) 400-0700
F: (510) 400-0799
www.questcor.com
Circle # 109
See our ad on page 4

RedBarn Enterprises
6225 North 16th Avenue
Phoenix, AZ 85015
P: (800) 577-1317
F: (602)-242-9211
www.red-enter.com
Circle # 111
See our ad on page 88

Special Needs Advocate for Parents (SNAP)
1801 Avenue of the Stars #401
Los Angeles, CA 90067
P: (888) 310-9889
F: (310)-201-9889
www. snapinfo.org
Circle # 117
See our ad on page 197

OTHER/CAR SEATS & SAFETY RESTRAINTS

E-Z-ON Products Inc. of Florida
605 Commerce Way West
Jupiter, FL 33458
P: 800-323-6598
F: 561-747-8779
www.ezonpro.com
Dynamically tested transportation safety restraints, including supportive, Adjustable E-Z-ON(tm) Vest & Modified Vest for children who must ride lying down. Custom solutions available.

OTHER/CHILD SECURITY

Care Electronics
4700 Sterling Drive, Ste. D
Boulder, CO 80301
(303) 444-2273
www.careelectronics.com

OTHER/CHILDREN'S HOSPITALS

NYU/Hospital for Joint Diseases Center for Children
301 East 17th Street
New York, NY 10003
P: (212) 598-2330
www.jointdiseases.com
Circle # 127
See our ad on page 15

OTHER/DEAF/BLIND

National Family Association for Deaf-Blind
111 Middle neck Road
Sands Point, NY 11050-1129
P: (800) 255-0411 ext. 275
F: (516) 944-7302
email: nfadb@aol.com
www.nfadb.org
Circle # 98
See our ad on page 192

OTHER/HYPERBARIC THERAPY

Ocean Hyperbaric Neurologic Center
4001 Ocean Drive
Lauderdale-by-the-Sea, FL 33308
P: (954) 771-4000
F: (954) 776-0670
e-mail: info@oceanhbo.com
www.oceanhbo.com
Circle # 100
See our ad on page 126

OTHER/LEGAL

Lawyers, Incorporated, P.C.
P: 1-800-888-LAWS
www.lawyersincorporated.com
Circle # 82
See our ad on page 90

OTHER/MONITORING SYSTEM

Care Electronics
4700 Sterling Drive, Suite D
Boulder, CO 80301
P: (303) 447-2273
www.careelectronics.com

OTHER/MUSIC

Center for Creative Play
1400 South Braddock Avenue
Pittsburgh, PA 15218
P: 412-371-1668
F: 412-371-1096
Circle # 48
See our ad on page 177

Send us your child's photo, essay or artwork!
EP is always looking for submissions for our monthly *Children's Page* and *Familiar Faces* Columns. Send to:
Exceptional Parent
65 East Route 4,
River Edge,
NJ 07661

We Like Making Kids Happy...

Send For Free Catalog

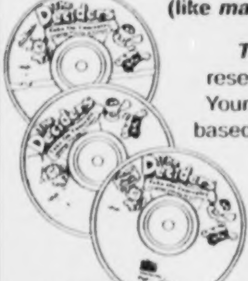
equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax: (781) 275-4094

Circle #55or visit www.eparent.com/adinfo

Want Software That Expands Your Child's Basic Concept Skills?

Get a FREE DEMO of *The Deciders Take On Concepts* series today!

Help Your Child Learn Over 130 Essential Language Concepts (like *many/few* & *same/different*)



The Deciders Take On Concepts is research-based software for ages 4–10. Your child will love the motivating, story-based design with interactive exploration!

You'll want all 3 exciting ***Deciders*** missions (CD-ROMs)! $59 each (Home Version)

Call 1-800-225-4769 for your **FREE *Deciders* demo CD-ROM** or for a **FREE catalog!**

Mention Code 70EP

THINKING PUBLICATIONS®

www.ThinkingPublications.com • Fax 1-800-828-8885
424 Galloway Street • Eau Claire, WI 54703
COMMUNICATION SOLUTIONS THAT CHANGE LIVES®

Circle #130 or visit www.eparent.com/adinfo

PRODUCT & SERVICES DIRECTORY

OTHER/NEWBORN SCREENING

Perkin Elmer Life Sciences, Inc.
3985 Eastern Road
Norton, OH, 44203
P: 330-825-4525
F: 330-825-8520
www.perkinelmer.com
PerkinElmer Life Sciences, Inc. is the leading supplier of analytical equipment, reagents and software systems to newborn screening laboratories, worldwide. With an extensive research and development portfolio, PerkinElmer has pioneered the expansion of newborn screening for such tests as sickle cell anemia, congenital hypothyroidism, metabolism (amino acids, fatty acids and organic acids) and others. Please contact your State Department of Health for more information regarding newborn screening.
Circle # 105
See our ad on page 149

OTHER/PEDIATRIC MOBILITY

Innovative Products Inc.
830 South 48th St
Grand Forks ND 58201
P: (701) 772-5185 or (800) 950-5185
F: (701) 772-5284
www.iphope.com
Circle # 77
See our ad on page 81

OTHER/RESEARCH STUDIES

National Institute of Mental Health Pediatrics and Developmental Neuropsychiatry
9000 Rockville Pike
Building 10 Room 4N208, MSC 1255
Bethesda, MD 20892
P: (301)496-5323
F: (301) 402-8497
www.intramural.nimh.nih.gov/research/pdn/index.htm
Circle # 96
See our ad on page 176

OTHER/TRANSITIONAL CARE

Children's Hospital
Transitional Care Unit (TCU)
2924 Brook Road
Richmond, Virginia 23220
P: (804) 228-5818
F: (804) 228-5808
www.childrenshosp-richmond.org
Pediatric subacute/long-term care. TCU offers supportive training environment for parents and caregivers.
Circle # 38
See our ad on page 79

PERSONAL CARE PRODUCTS

Advanced Respiratory, Inc.
1020 West County Rd F
St. Paul, MN 55126
P: 1-866-411-VEST
www.thevest.com
Manufacturer of The Vest TM Airway Clearance System, a home-use device utilizing high-frequency chest wall oscillation (HFCWO) to loosen, thin, and clear mucus from airways.
Circle # 18
See our ad on page 3

Hard Manufacturing
230 Grider Street
Buffalo, NY 14215
P: (800) 873-4273
F: (716) 896-2579
www.hardmfg.com
Circle # 69
See our ad on page 16

Maddak Inc.
6 Industrial Road
Pequannock, NJ 07440
P: (973) 628-7600
F: (973) 305-0841
www.maddak.com
Circle # 86
See our ad on page 179

Sage Products, Inc.
3909 Three Oaks Road, Cary, IL 60013
P: (800) 323-2220
F: (815) 455-5599
e-mail: customerservice@sageproducts.com
www.comforthbath.com
Circle # 113
See our ad on page 153

PHARMACEUTICAL PRODUCTS/SERVICES

Athena Diagnostics
Four Biotech Park
377 Plantation Street
Worcester, MA 01605
P: 800-394-4493
F: 508-753-5601
www.athenadiagnostics.com
Athena Diagnostics is a leader in testing for neurological disorders. Our expertise includes diagnosis in the areas of: peripheral nerve disorders, neurogenetic disorders, Alzheimer's disease, paraneoplastic syndromes, movement disorders, neuromuscular disorders, and ataxia. Ask your doctor about Athena.
Circle # 25
See our ad on page 21

Genzyme Therapeutics Divison
Medical Information Services
One Kendall Square
Cambridge, MA 02139
P: 800-745-4447
www.genzyme.com
Circle # 63
See our ad on page 2

Novazyme Pharmaceuticals Inc.
353 Nassau Street
Princeton, NJ 08540
P: 609-683-4400
www.novazyme.com
Circle # 63
See our ad on page 2

Questcor Pharmaceuticals, Inc.
3260 Wipple Road
Union City, CA 94587
P: (510) 400-0700
F: (510) 400-0799
www.questcor.com
Circle # 109
See our ad on page 4

PUBLISHERS

Charles C. Thomas, Publisher, Ltd.
2600 South First Street
Springfield, IL 62704
P: 800-258-8980
F: 217-789-9130
e-mail books@ccthomas.com
www.ccthomas.com
Circle # 36
See our ad on page 105

Thinking Publications
424 Galloway Street
Eau Claire, WI 54703
P: 800-225-GROW (4769)
F: 800-828-8885
www.thinkingpublications.com
Circle # 130
See our ad on page 189

Jason & Nordic
P.O. Box 441
Hollidaysburg, PA 16648
P: (814) 696-2920
F: (814) 696-4250
www.jasonandnordic.com

Woodbine House
Publisher of the Special Needs Collection
6510 Bells Mill Road
Bethesda, MD 20817
P: (800) 843-7323
F: (301) 897-5838
www.woodbinehouse.com
See our ad on page 201

RAMPS/LIFTS

Barrier Free Lifts
9230 Prince William St
Manassas, VA 20110
P: 800-582-8732
F: 703-361-7861
www.bfl-inc.com
Circle # 26
See our ad on page 74

Guldmann Inc.
5505 Johns Road, Suite 700
Tampa, FL 33634
P: 800-664-8834
F: 813-880-9558
www.guldmann.com
e-mail: info@guldmann.net
Circle # 66
See our ad on page 146

Handicaps, Inc.
4335 So. Santa Fe Dr.
Englewood, CO 80110
P: (800)782-4335
F: (303)761-6811
http://www.handicapsinc.com
Circle # 68
See our ad on page 174

Liberty Motor Company Inc.
2390 South Service Road West
Oakville, ON L6L 5M9
P: 888-578-8886
F: 905-465-3965
email: sales@libertymotorco.com
www.libertymotorco.com
Circle # 83
See our ad on page 121

Moving Solutions
2550 Wisconsin Avenue
Downers Grove, IL 60561
P: (800) 228-7980
F: (630) 963-9693
Email: movingsolution@aol.com
Moving Solutions features Faaborg Lifts and the Highway Overhead Transfer System. Both designed to move patients comfortably, safely and reliably while being easy to use and maneuver.

Ride-Away Corp.
51 Wentworth Avenue
Londonderry, NH 03053
P: (888) Ride-Away
F: (603) 432-1549
www.ride-away.com
Other locations include N. Attleboro, MA, E. Hartford, CT and Essex Junction, VT

Sure Hands Lift & Care Systems
982 Route 1
Pine Island, NY 10969
P: (800) 724-5305
F: (845) 258-6634
email: info@surehands.com
www.surehands.com
Circle # 123
See our ad on page 148

REHABILITATION CENTER/HOSPITAL

Children's Hospital
2924 Brook Road
Richmond, Virginia 23220
P: (804) 228-5818
F: (804) 228-5808
www.childrenshosp-richmond.org
Comprehensive Pediatric Inpatient & Outpatient Rehabilitation Services and Transitional Care; Physician Specialty Clinics; Multiple Locations.
Circle # 38
See our ad on page 79

Cumberland Hospital for Children and Adolescents
9407 Cumberland Road
New Kent, VA 23124
(800) 368-3472 (804) 966-5639
Cumberland Hospital provides comprehensive medical, behavioral, and educational services to youth ages 2-22.

Advanced Respiratory, Inc.
1020 West County Rd F
St. Paul, MN 55126
P: 1-866-411-VEST
www.thevest.com
Manufacturer of The Vest TM Airway Clearance System, a home-use device utilizing high-frequency chest wall oscillation (HFCWO) to loosen, thin, and clear mucus from airways.
Circle # 18
See our ad on page 3

Cleveland Clinic Children's
Hospital for Rehabilitation
2801 Martin Luther King Jr. Dr.
Cleveland, OH 44104
P: (800) 635-2417
F: (216) 791-1012
Pediatric rehabilitation hospital caring for children with chronic illnesses & disabilities caused by trauma, birth defects, brain and spinal cord injury, and respiratory, orthopedic, neuromuscular and developmental disorders.

Florida Institute for Neurological Rehabilitation, Inc.
P.O. Box 1348
Wauchula, FL 33873
P: 863-773-2857 or 800-697-5390
F: 863-773-2638
e-mail: thi@finr.org
www.finr.org
State licensed, CARF & JCAHO accredited post-acute rehabilitation facility specializing in treatment of children and adults with TBI or another form of neurologic impairment, especially those with behavioural difficulties. Specialized Pediatric Program with Accredited School.
Circle # 58
See our ad on page 106

Kennedy Krieger Institute
707 North Broadway
Baltimore, MD 21205
P: 888-554-2080
F: 410-502-8951
www.kennedykrieger.org
Circle # 80
See our ad on page 193

Matheny School and Hospital
P.O. Box 339, Main Street
Peapack, NJ 07977
P: (908) 234-0011
e-mail: info@matheny.org
www.matheny.org
Circle # 88
See our ad on page 168

Miami Children's Hospital
3100 SW 62nd Avenue
Miami, Florida 33155
(305) 930-4KIDS

Miami Children's Hospital Dan Marino Center
2900 S. Commerce Parkway
Weston, Florida 33331
(954) 385-6274
www.mch.com
Autism, ADD, neurological disorders, cerebral palsy, Down's syndrome, spina bifida, scoliosis, phys/occup therapy.

NYU/Hospital for Joint Diseases Center for Children
301 East 17th Street
New York, NY 10003
P: (212) 598-2330
www.jointdiseases.com
Circle # 127
See our ad on page 15

Pathways Awareness Foundation
P: 800-955-2445
F: 888-795-5884
TTY: 800-326-8154
e-mail: friends@pathwaysawareness.org
www.pathwaysawareness.org
Circle # 103
See our ad on page 68

Questcor Pharmaceuticals, Inc.
3260 Wipple Road
Union City, CA 94587
P: (510) 400-0700
F: (510) 400-0799
www.questcor.com
Circle # 109
See our ad on page 4

Toronto Hyperbaric
101 Queensway West, Suite 100
Mississauga, Ontario
Canada L5B 2P7
P: 905-306-0770
F: 905-306-0127
www.torontohyperbaric.com
Circle # 131
See our ad on page 78

SCHOOLS/CAMPS/RESIDENCES

Ability Camp, Inc.
Center for Conductive Education and Hyperbaric Oxygen Therapy. Providing separate and combined programs for children with C.P. For a free video call 1-800-442-6992
www.abilitycamp.com
Circle # 16
See our ad on page 203

Annandale Village
3500 Annandale Lane
Suwanee, GA 30024
P: (770) 945-8381
F: (770) 945-8693
www.annandale.org
Full residential and day programs paid vocational training, job placement, recreational activities, case mgt., creative and performing arts, meals and counseling.
Circle # 22
See our ad on page 36

Anne Carlsen Center for Children
301 7th Avenue NW
Jamestown, ND 58401
(800) 568-5175
Phone/Fax (701) 252-3850
www.annecenter.org
Educational, therapeutic and residential services through age 21. Our evaluation team travels to your home and school setting.
Circle # 23
See our ad on page 146

Benedictine Programs & Services
14299 Benedictine Lane
Ridgely, MD 21660
410-634-2112
Fax: 410-634-2640
www.benschool.com

Berkshire Hills Music Academy
48 Woodbridge St.
S. Hadley, MA 01075
P: (413) 540-9720
F: (413) 534-3875
www.berkshirehills.org
Music studies for young adults with LD

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 02136
P: (413) 528-2523
F: (413) 528-0293
For people of all ages with severe developmental delay. They may be medically involved. We offer comprehensive and integrated medical residential and educational services. All therapeutic services are included.
www.berkshiremeadows.org
Circle # 28
See our ad on page 70

Bethesda Lutheran Homes & Services, Inc.
700 Hoffmann Dr
Watertown, WI 53094
P: (800) 369-4636
F: (920) 262-6513
http://www.blhs.org
Circle # 29
See our ad on page 198

Beverly Farm Foundation
6301 Humbert Road
Godfrey, IL 62035
P: (618) 466-0367
e-mail: jhaycraft@beverlyfarm.org
www.beverlyfarm.org
Circle # 30
See our ad on page 171

Boston Higashi School
800 North Main St.
Randolph, MA 02368
P: (781) 961-0800, ext. 109
F: (781) 961-3466
www.bostonhigashi.org
The International Program Serving Individuals with Autism. Affiliate Musashino Higashi Gakuen, Japan

Brehm Preparatory School
1245 E. Grand Ave
Carbondale, IL 62901
P: 618.457.0371
F: 618.529.1248
www.brehm.org
Boarding school for students with learning disabilities 6-12. Post-secondary program for students at the junior college level.

Bridge School
545 Eucalyptus Avenue
Hillsborough, CA 94010
(650) 696-7295, (650) 342-7598
www.bridgeschool.org
The Bridge School serves individuals who use AAC and AT. We operate a K-8 school program as well as many outreach projects including Building Bridges Camp.

Camp Lee Mar
805 Redgate Road
Dresher, PA 19025
P: (215) 658-1708
F: (215) 658-1710
e-mail gtour400@aol.com
www.leemar.com

Camphill Special School
1784 Fairview Road
Glenmoore, PA 19343
(610) 469-9236
Fax: (610) 469-9758
www.beaverrun.org
e-mail: bvrm@aol.com
Circle # 35
See our ad on page 203

Center for Discovery (SDTC)
Box 8400 Benmosche Road
Harris, NY 12742
P: (845) 794-1400
F: (845) 794-1474
www.sdtcdiscovery.org
Offering people with significant disabilities and their families, innovative and comprehensive educational, clinical, social and residential experiences designed to enrich their lives through personal accomplishments and increased independence.
Circle # 126
See our ad on page 91

Children's Care Hospital & School
2501 W. 26th Street
Sioux Falls, SD 57105-2498
(605) 782-2300 or (800) 584-9294
Private, nonprofit facility with outreach, outpatient, day & summer school and residential services for children with disabilities. Pediatric & adult outpatient services now offered at the CCHS Rehabilitation Center, 1100 W. 41st Street. Accredited rehabilitation programs.
http://www.cchs.org
Circle # 37
See our ad on page 203

Chileda Institute
1020 Mississippi Street
LaCrosse, WI 54601
P: (608) 782-6480
F: (608) 782-6481
www.chileda.org
Circle # 39
See our ad on page 181

Cotting School
453 Concord Avenue
Lexington, MA 02421
P: (781) 862-7323
e-mail: jbrownsmith@cotting.org
www.cotting.org &
www.cottinghopehouse.org
A day school for students with physical, learning, medical and communication challenges.

Crotched Mountain Rehabilitation Center
1 Verney Drive
Greenfield, NH 03047
P: (603) 547-3311
F: (603) 547-3232
Fully accredited by the NEASC and CARF, the Crotched Mountain Rehabilitation Center offers the very best of residential and day programs for children with complex special needs. Visit our Internet site at
http://www.cmf.org
Circle # 49
See our ad on page 77

Dr. Gertrude A. Barber Center
136 East Avenue
Erie, PA 16507
P: (814) 453-7661
F: (814) 454-2771
e-mail: gabcmain@drbarbercenter.org
Educational/residential/vocational/employment facility serving children and adults with disabilities with state of the art programming.

Elwyn
111 Elwyn Road
Elwyn, PA 19063
P: 610.891.2196
F: 610.891.2903
www.elwyn.org
150 years of educating children with special needs; day and residential options from birth to age 21, early intervention, integrated preschool, elem., secondary and alternative Ed with clinical supports, physical, recreational and adjunctive therapies; continuum services available after schooling years.

Evergreen Center
345 Fortune Boulevard
Milford, MA 01757
P: (508) 478-2631
F: (508) 634-3251
www.evergreenctr.org
e-mail: services@evergreen.org
Circle # 56
See our ad on page 174

Florida Institute for Neurological Rehabilitation, Inc.
P.O. Box 1348
Wauchula, FL 33873
P: 863.773.2857 or 800.697.5390
F: 863.773.2638
e-mail: tbi@finr.org
www.finr.org
State licensed, CARF & JCAHO accredited post-acute rehabilitation facility specializing in treatment of children and adults with TBI or another form of neurologic impairment, especially those with behavioural difficulties. Specialized Pediatric Program with Accredited School
Circle # 58
See our ad on page 106

Heartspring
8700 East 29th Street N.
Wichita, KS 67226
P: (800) 835-1043
Fax: (316) 634-0555
Our campus provides a positive, practical environment for multidisciplinary programs that include education, life skills, communication, and behavior management. We serve children ages 5-21 with multiple disabilities.
www.heartspring.org
Circle # 24
See our ad on page 89

Empower & Enable
Discover REAL Fun and Excitement
With Family and Friends
Team Xtreme® makes it possible for you to play Nintendo® video games, full speed, with anyone! Even using just one switch!

All while working on
Social Skills
Self Confidence
Motor Movements
Hand-eye coordination
Your Communications Skills
Switch use for Environmental Control
And having FUN just like everybody else!

Official Nintendo Seal of Quality
Officially tested, approved, and licensed by Nintendo of America Inc.

E-mail or call for our no obligation, FREE VIDEO showing Team Xtreme in Action.

FREE monthly Internet E-newsletter, the PDG E-news. It's fun, informative, special offers. Visit our web site for details.

We carry a large variety of high quality switches. Other exciting products are being developed!

Pathways Development Group, Inc.
17409 - 57th Ave W, Lynnwood, Washington 98037 USA
http://www.pathwaysdg.com pdg@pathwaysdg.com
Toll Free US and Canada 1-877-742-4604
or 425-742-4674

Circle #104 or visit www.eparent.com/adinfo

Everyone can Participate... Learn... & Communicate!

At AbleNet, Inc., we believe all children, no matter their abilities, should have meaningful opportunities to participate, learn and communicate. Call today for our 40 page catalog–packed with simple assistive technology and activity ideas–and discover how your child can participate in any activity at home, school and in the community.

ableNet
Call for a free AbleNet Catalog!
1-800-322-0956
Mention Code EPRG02

Shop AbleNet online at www.ablenetinc.com

Circle #17 or visit www.eparent.com/adinfo

PRODUCT & SERVICES DIRECTORY

HMS School for Children
with Cerebral Palsy
4400 Baltimore Avenue
Philadelphia, PA 19104
P: (215) 222-2566
F: (215) 222-1889
Circle # 73
See our ad on page 76

IDDI, Crystal Springs School
38 Narrows Road
Assonet, MA 02702
P: (800) 840-8087 ext. 375
F: (508) 644-2008
e-mail: Css372@aol.com
Circle # 50
See our ad on page 194

Judge Rotenberg Educational Center
240 Turnpike Street
Canton, MA 02021
P: (781) 828-2202
F: (7810 828-2804
e-mail: k.lachance@judgerc.org
www.judgerc.org
Circle # 79
See our ad on page 78

Kennedy Krieger Institute
707 North Broadway
Baltimore, MD 21205
P: 888-554-2080
F: 410-502-8951
www.kennedykrieger.org
Circle # 80
See our ad on page 193

Martha Lloyd Community Services
190 West Main Street
Troy, PA 16947
P: (570) 297-2185
F: 570-297-1019
e-mail: information@marthalloyd.org
www.marthalloyd.org
Circle # 87
See our ad on page 88

Matheny School and Hospital
P.O. Box 339, Main Street
Peapack, NJ 07977
P: (908) 234-0011
e-mail: info@matheny. org
www.matheny.org
Res., outpt., ed (3-21), respite for d.d.
Circle # 88
See our ad on page 168

Melmark, Inc.
2600 Wayland Road
Berwyn, PA 19312
P: 1-888-MELMARK
F: (610) 353-4956
www.melmark.org
Approved private school with 24-hour learning model, adult day programs, & residential alternatives for children & adults with dev. disabilities. 24- hour nursing care, OT/PT, adaptive therapies, aquatics, hippotherapy, recreation, & multi-sensory programs.
Circle # 92
See our ad on page 158

New England Center for Children
33 Turnpike Road
Southboro, MA 01772
P: (508) 481-1015
F: (508) 485-3421
www.necc.org
State of the art day/residential school and group homes for children with autism, PDD, developmental disabilities & behavior disorders, age 3-22. Curriculum covers communication, academics, social & life skills, employment. Recipient of U.S. Dept. of Education's National Award for Model Professional Development.

New England Village, Inc.
664 School Street
Pembroke, MA 02359
P: (781) 293-5461
F: 781-294-8385
e-mail: jandracchio@newengland village.org
www.newenglandvillage.org
See our ad on page 10

Pathfinder Village
for Down Syndrome
3 Chenango Road
Edmeston, NY 13335
P: (607) 965-8377
e-mail: info@pathfindervillage.org
www.pathfindervillage.org
Circle # 102
See our ad on page 198

Porter Sargent Publishers Inc.
11 Beacon St Suite 1400
Boston MA 02108-3099 USA
P: 800-342-7470
F: 603-669-7945
www.portersargent.com
The Directory for Exceptional Children & other guides for professionals & parents seeking the most appropriate school/program
See our ad on page 202

Riverbrook Residence, Inc.
4 Ice Glen Road, P.O. Box 478
Stockbridge, MA 01262
P:(413) 298-4926
F: (413) 298-5166
e-mail: riverbro@berkshire.net
www.riverbrook.org
Serving women with MR Opportunities for voc., social and creative growth. Shared living in integrated community setting 24 hr. supports.

St. Vincent's Special Needs Services
95 Merritt Blvd.
Trumbull, CT 06611
P: (203) 375-6400
F: (203) 380-1190
e-mail: feroleto.child.dev@snet.net
Providing education and therapeutic day programs for children, 0-21 with multiple medical/developmental needs.
Circle # 121
See our ad on page 199

Stewart Home School
4200 Lawrenceburg Road Dept. 8
Frankfort, KY 40601
P: (502) 227-4821
F: (502) 227-3013
www.stewarthome.com
Circle # 122
See our ad on page 199

Texas NeuroRehabilitation Center
1106 West Dittmar Road
Austin, TX 78745
P: (800) 252-5151 or (512) 444-4835
F: (512) 462-6636
Providing brain injury/ neurobehavioral treatment for children & adolescents with complex medical, physical and/or behavioral issues.

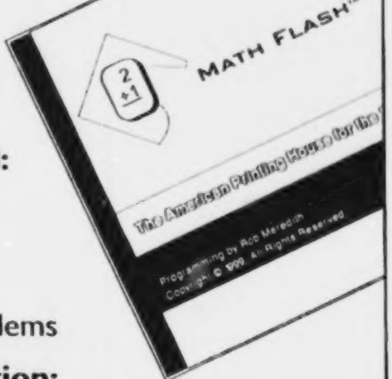
Toronto Hyperbaric
101 Queensway West, Suite 100
Mississauga, Ontario
Canada L5B 2P7
P: 905-306-0770
F: 905-306-0127
www.torontohyperbaric.com
Circle # 131
See our ad on page 78

Upward Bound Camp for Persons With Special Needs
P.O. Box C
Stayton, OR 97383
P: (503) 897-2447
F: (503) 897-4116
ACA accredited Christian program serving persons 12 yrs-80+ yrs w/primary label of MR/DD skilled staff, fun & friends year round camp & respite.

Math Flash™

Math Flash™ improves addition, subtraction, multiplication, division skills on the PC through:

- Instruction
- Drills
- Practice


MATH FLASH™
2
+1
The American Printing House for the Blind
Programming by Rob Meredith
Copyright © 1999 All Rights Reserved

Easily modified:

- Number of exercises
- Degree of difficulty
- Custom problems

Dual Presentation:

- Professionally narrated digital speech (not synthesized)
- Large print on screen

APH
800.223.1839
www.aph.org

Circle #21 or visit www.eparent.com/adinfo

NFADB

National Family Association for Deaf-Blind is a non-profit, volunteer-based family association. Our philosophy is that *individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community.*

NFADB is the largest national network of families focusing on issues surrounding deaf-blindness. Using a team of eleven Regional Directors and an Executive Committee, we advocate for all persons who are deaf-blind of any age and cognitive ability. We publish a tri-annual newsletter; support national policies to benefit people who are deaf-blind; collaborate with professionals; work with national projects; and maintain a website with a chatroom and listserv for members.

For more information or to contact your Regional Director:

NFADB
111 Middle Neck Road
Sands Point NY 11050
1-800-255-0411 ext 275
NFADB@aol.com
www.NFADB.ORG

Ralph Warner, **President**
Peg Pedersen, **Vice President**
Pat McCallum, **Secretary**
Linda Syler, **Treasurer**

Region 1 CT MA ME NH RI VT
Region 2 NJ NY PR VI
Region 3 DC DE MD PA VA WV
Region 4A AL FL GA MS
Region 4B KY NC SC TN
Region 5 IL IN OH MI MN WI
Region 6 AR LA NM OK TX
Region 7 IA KS MO NE
Region 8 CO MT ND SD UT WY
Region 9 AZ CA HI NV
Region 10 AK ID OR WA

NFADB is supported in part by the Helen Keller National Center, Sands Point, NY and the Hilton/Perkins Program of Perkins School for the Blind, Watertown, MA. The Hilton/Perkins Program is funded by a grant from the Conrad N. Hilton Foundation of Reno, Nevada.

Circle #98 or visit www.eparent.com/adinfo

PRODUCT & SERVICES DIRECTORY

SEATING & POSITIONING

Abilitations
1 Sportime Way
Atlanta, GA 30340
P: (800) 850-8602
F: (800) 845-1535
www.abilitations.com
Circle # 120
See our ad on page 81

Adaptivemall.com
15 South 2nd Street, Box 0082
Dolgeville, NY 13329
P: 866-529-8407
F: 315-429-8862
www.adaptivemall.com
Circle # 27
See our ad on page 146

Altimate Medical Inc.
PO Box 180, 262 West 1st ST
Morton, MN 56270
P: 507-697-6393 or 800-342-8968
F: 507-697-6900
email: info@easystand.com
www.easystand.com
Circle # 20
See our ad on page 76

Bodypoint Design, Inc.
558 First Avenue South Suite 300
Seattle, WA 98104
P: (800) 547-5716
F: (206) 405-4556
www.bodypoint.com
Circle # 32, 33, 34
See our ad on page 99, 148, 175

Columbia Medical Mfg. Corp.
PO Box 633
Pacific Palisades, CA 90272
P: (800) 454-6612
F: (310) 305-1718
www.columbiamedical.com
Circle # 41
See our ad on page 20

Consumer Care Products Inc.
1446 Pilgrim Rd
Plymouth, WI 53073
P: 920-893-4614
F: 920-893-6195
www.consumercareinc.com
Circle # 43
See our ad on page 176

Convaid
2830 California Street
Torrance, CA 90503
P: (310) 618-0111
F: (310) 618-8811
www.convaid.com
Circle # 44
See our ad on page 35

Equipment Shop
P.O. Box 33
Bedford, MA 01730
P: 800-525-7681
F: 781-275-4094
www.equipmentshop.com
We sell Tripp Trapp chairs from Norway in 8 colors. Accessories like tray, lap belt and pommel make the famous adjustable chair extremely versatile.
Circle # 55
See our ad on page 189

E-Z-ON Products Inc. of Florida
605 Commerce Way West
Jupiter, FL 33458
P: 800-323-6598
F: 561-747-8779
www.ezonpro.com
Dynamically tested transportation safety restraints, including supportive, Adjustable E-Z-ON(tm) Vest & Modified Vest for children who must ride lying down. Custom solutions available.

FlagHouse
601 FlagHouse Drive
Hasbrouck Heights, NJ 07604-3116
P: (800) 793-7900
F: (800) 793-7922
e-mail: sales@flaghouse.com
www.flaghouse.com
Circle # 57
See our ad on page 1

Freedom Designs Inc.
2741 Madera Road
Simi Valley, CA 93065
P: (800) 331-8551 or (805) 582-0077
F: (805) 832-1473
Circle # 60
See our ad on page 75

Invacare Corporation
PO Box 4028
Elyria, OH 44036-2125
(800) 333-6900
e-mail: info@invacare.com
www.invacare.com
Invacare Corporation is the global leader in the manufacture and distribution of innovative medical products which promote recovery and active lifestyles.

Kids Project, Pine Tree Society
P.O. Box 518
Bath, ME 04530
P: (207) 443-3341
F: (207) 443-1070
www.pinetreesociety.org
kidsproject@pinetreesociety.org
Affordable, high quality adaptive equipment. Custom furniture and prescriptive equipment available.

Exceptional children deserve exceptional care.

The best help for cerebral palsy, spina bifida and related disorders is at Kennedy Krieger Institute.

For 61 years, Kennedy Krieger Institute has been the leader in helping children with severe disabilities. Focusing on early identification, intervention and treatment, our state-of-the-art interdisciplinary team approach—combined with a caring, supportive touch—has enabled generations of children to live their lives to the fullest.

Our comprehensive assessment and treatment for children with cerebral palsy, spina bifida and related disorders includes: Neurology, Medical Services, Nursing, Urology, Orthopedics, Physical Therapy, Occupational Therapy, Orthotist, Clinical Psychology, Neuro-Psychology, Seating, Feeding, as well as Rhizotomy, Spasticity and Movement Disorder clinics.

And unlike many programs, we see patients beyond age 18. Call Kennedy Krieger Institute today. We're here to help.

Kennedy Krieger Institute
707 North Broadway • Baltimore, MD 21205
www.kennedykrieger.org

1-888-554-2080
Kennedy Krieger Institute's Toll-Free Referral Line

Circle #80or visit www.eparent.com/adinfo

PRODUCT & SERVICES DIRECTORY

Matheny School and Hospital
P.O. Box 339, Main Street
Peapack, NJ 07977
P: (908) 234-0011
e-mail: info@matheny.org
www.matheny.org
Circle # 88
See our ad on page 168

Medi-Fair, Inc.
25 Jefferson Street
Monticello, NY 12701
P: (800) 282-6334 or (845) 342-3003
F: (845) 794-0712
www.medifair.com
Circle # 90
See our ad on page 177

Mulholland Positioning Systems, Inc.
215 North 12 Street
Santa Paula, CA 93061
P (800-543-4769)
F: 805-933-1082
www.mulhollandinc.com
Circle # 94, 95
See our ad on page 169, 181

Otto Bock Health Care
2 Carlson Parkway North, Suite 100
Minneapolis, MN 55447-4467
P: 763 553 9464
F: 763 519 6153
www.ottobockus.com
Circle # 101
See our ad on page 147

Permobil, Inc.
6961 Eastgate Blvd
Lebanon, TN 37090
P: 1 800 736 0925
F: 1 800 231 3256
www.permobil.com
Manufacturing in Sweden since 1968, Permobil continues to develop the most durable and technically sophisticated power wheelchairs in the world. Available with a variety of seating choices, Permobil chairs are long-lasting and offer a wide selection of features that can be customized to fit the individuals needs.
Circle # 106
See our ad on page 19

Quantum™ Dynamo™/Dynamo ATS
Versa Seat standard
Accepts tilt seating systems
Seating as small as 10"x10"
www.quantumrehab.com
Circle # 108
See our ad on page 101

R.E.A.L. Design Inc.
187 South Main St.
Dolgeville, NY 13329
P: (800) 696-7041
F: (315) 429-3071
www.realdesigninc.com
Circle # 110
See our ad on page 195

Sammons Preston
4 Sammons Court
Bolingbrook, IL 60440
P: 800-323-5547
F: 800-547-4337
email: sp@sammonspreston.com
www.sammonspreston.com
Circle # 114
See our ad on page 46

Snug Seat
12801 E. Independence Blvd.
Stallings, NC 28105
P: 1-800-336-7684
F: 704-882-0751
www.snugseat.com
Circle # 118
See our ad on page 5

Wenzelite Re/hab Supplies
220 36th Street
Brooklyn, NY 11232
P: (718) 768-8002
F: (718) 768-8020
www.wenzelite@aol.com
Circle # 136
See our ad on page 88

Theradapt Products, Inc.
17W163 Oak Ln.
Bensenville, IL 60106
P: 800-261-4919
F: 630-834-2478
www.theradapt.com
From early intervention through adolescence we offer a complete line of adjustable, therapeutic positioning chairs and standers.
Circle # 128
See our ad on page 125

SOFTWARE

DynaVox Systems LLC
2100Wharton St.
Pittsburgh, PA 15203
P: 412-381-4883 F: 412-381-5241
www.dynavoxsys.com
Circle # 54
See our ad on page 44

Vcom3D, Inc.
3452 Lake Lynda Drive, Suite 260
Orlando, FL 32817
P: (407)737-7310 x111
F: (407)737-6821
e-mail: signingavatar.com
www.signingavatar.com

SPORTS/RECREATION/FAMILY

Bike-on
54 Tiffany Road
Coventry, RI 02816
P: 888-424-5366
F: 401-821-7544
email: info@bike-on.com
www.bike-on.com
Circle # 31
See our ad on page 179

Disability Options, Inc.
P.O. Box 1967
Palmer, AK 99645
P: (907) 745-3900
F: (907) 746-3060
www.disabilityoptions.com

FlagHouse
601 FlagHouse Drive
Hasbrouck Heights, NJ 07604-3116
P: (800) 793-7900
F: (800) 793-7922
e-mail: sales@flaghouse.com
www.flaghouse.com
Circle # 57
See our ad on page 1

Freedom Concepts Inc.
"Making Mobility A Reality"
P.O. Box 45117 RPO Regent
Winnipeg, Manitoba R2C 5C7
P: 800-661-9915 or 204-654-1074
F: 204-654-1149
email: mobility@freedomconcepts.com
www.freedomconcepts.com
Circle # 59
See our ad on page 115

Innovative Products
830 S. 48th Street
Grand Forks, ND 58201
P: 701-772-5185 or 800-950-5185
F: 701-772-5284
email: psteinke@iphope.com
Circle # 77
See our ad on page 81

National Sports Center for the Disabled
P.O. Box 1290
Winter Park, CO 80482
P: (970) 726-1540
F: (970) 726-4112
http://www.nscd.org

Pathways Development Group, Inc.
17409 - 57th Avenue West
Lynnwood, WA 98037
P: 1(877) 742-4604
F: (425) 745-9279
www.pathwaysdg.com
Circle # 104
See our ad on page 191

Rock N' Roll Therapy Cycles
P.O. Box 1558
Levelland, TX 79336
P: (800) 654-9664
F: (806) 894-1238
www.rocknrollcycles.com
e-mail:
funmachines@rocknrollcycles.com

You and those you serve are the inspiration behind what we do.

We are a national insurance and risk management firm insuring agencies that provide services to people with disabilities. We understand and actively engage ourselves in the efforts needed to achieve quality outcomes.

We also offer individual policies:

- ***Guardians/Care Managers Liability***
- ***Life Insurance for Individuals with disabilities***
- ***Residential Home Care Providers Liability***

If you need a referral to a provider agency in your area please contact us at 800.622.8272.

Written exclusively through independent agents/brokers

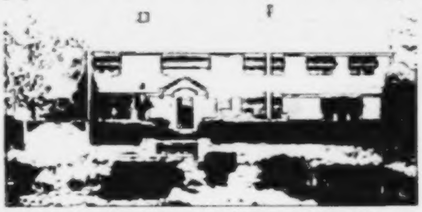
Package policies include:
Professional & General Liability,
Property, Crime, Auto & Umbrella

irwin siegel agency inc.
insurance & risk management
human service programs
800.622.8272 • siegelagency.com

Circle #78 or visit www.eparent.com/adinfo

Crystal Springs School

A PROGRAM OF THE
Institute for Developmental Diabilities, Inc.



Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeastern Massachusetts, close to Boston, Cape Cod, Providence and Newport, RI.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, Including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availablity.
- Licensed by the MA Office of Child Care Services.
- Approved by the MA Department of Education.
- Member of the MA Association of Approved Private Schools.

For information, Please Call Our Admissions Coordinator:
1-800-840-8087 (508) 644-3101 Ext: 375

Circle #50 or visit www.eparent.com/adinfo

568

Snug Seat
12801 E. Independence Blvd
Stallings, NC 28105
P: 1-800-336-7684
F: 704-882-0751
www.snugseat.com
Circle # 118
See our ad on page 5

Vital ID—Emergency Information Service
19845 Cabot Blvd
Haywood, CA 94545
P: (510) 521-4989
F: (510) 786-1120
www.vitalid.com

STANDING EQUIPMENT

Abilitations
1 Sportime Way
Atlanta, GA 30340
P: (800) 850-8602
F: (800) 845-1535
www.abilitations.com
Circle # 120
See our ad on page 81

Altimate Medical Inc.
PO Box 180, 262 West 1st ST
Morton, MN 56270
P: 507-697-6393 or 800-342-8968
F: 507-697-6900
email: info@easystand.com
www.easystand.com
Circle # 20
See our ad on page 76

Bodypoint Design, Inc.
558 First Avenue South Suite 300
Seattle, WA 98104
P: (800) 547-5716
F: (206) 405-4556
www.bodypoint.com
Circle # 32, 33, 34
See our ad on page 99, 148, 175

FlagHouse
601 FlagHouse Drive
Hasbrouck Heights, NJ 07604-3116
P: (800) 793-7900
F: (800) 793-7922
e-mail: sales@flaghouse.com
www.flaghouse.com
Circle # 57
See our ad on page 1

Medi-Fair, Inc.
25 Jefferson Street
Monticello, NY 12701
P: (800) 282-6334 or (845) 342-3003
F: (845) 794-0712
www.medifair.com
Circle # 90
See our ad on page 177

Mulholland Positioning System
215 No. 12th St., Box 391
Santa Paula, CA 93061
P: 800-543-4769
F: 805-933-1082
e-mail: customer_service@mulhollandinc.com
Circle # 94, 95
See our ad on page 169, 181

Permobil, Inc.
6961 Eastgate Blvd
Lebanon, TN 37090
P: 1.800.736.0925
F: 1.800.231.3256
www.permobil.com
Manufacturing in Sweden since 1968, Permobil continues to develop the most durable and technically sophisticated power wheelchairs in the world. Available with a variety of seating choices, Permobil chairs are long-lasting and offer a wide selection of features that can be customized to fit the individuals needs.
Circle # 106
See our ad on page 19

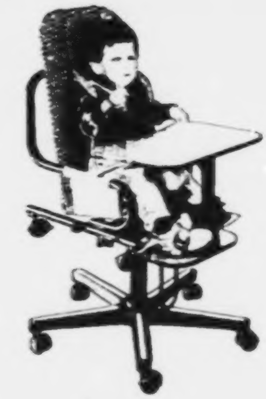
Sammons Preston
4 Sammons Court
Bolingbrook, IL 60440
P: 800-323-5547
F: 800-547-4337
email: sp@sammonspreston.com
www.sammonspreston.com
Circle # 114
See our ad on page 46

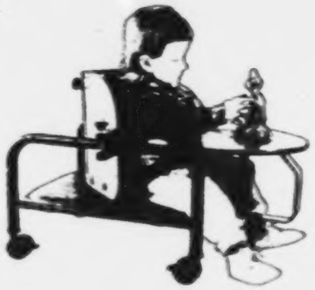
Snug Seat
12801 E. Independence Blvd.
Stallings, NC 28105
P: 1-800-336-7684
F: 704-882-0751
www.snugseat.com
Circle # 118
See our ad on page 5

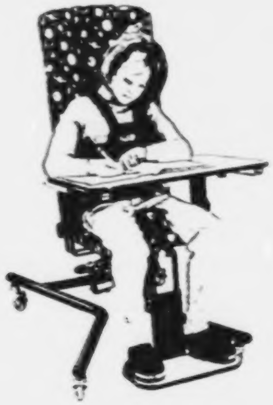
Theradapt Products, Inc.
17W163 Oak Ln.
Bensenville, IL 60106
P: 800-261-4919
F: 630-834-2478
www.theradapt.com
From early intervention through adolescence we offer a complete line of adjustable, therapeutic positioning chairs and standers.
Circle # 128
See our ad on page 125

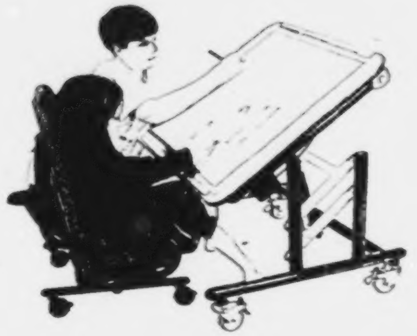
STROLLERS

Adaptivemall.com
15 South 2nd Street, Box 0082
Dolgeville, NY 13329
P: 866-529-8407
F: 315-429-8862
www.adaptivemall.com
Circle # 27
See our ad on page 146









The High-Low Chair
The Updown Chair

The LadyBug Corner Chair
The Convert-Able Table

Seating and
Positioning
Products
for Children

R.E.A.L. DESIGN
Rehab and Educational Aids for Living
Phone : 1-800-696-7041
Fax : 1-315-429-3071

Circle #110 or visit www.eparent.com/adinfo

PRODUCT & SERVICES DIRECTORY

Baby Jogger Company
1700 North 6th Street
Yakima, WA 98901
P:(509) 457-0925
F:(509) 453-7732
www.babyjogger.com
Circle # 125
See our ad on page 74

Bodypoint Design, Inc.
558 First Avenue South Suite 300
Seattle, WA 98104
P: (800) 547-5716
F: (206) 405-4556
www.bodypoint.com
Circle # 32, 33, 34
See our ad on page 99, 148, 175

Columbia Medical Mfg. Corp.
PO Box 633
Pacific Palisades, CA 90272
P: (800) 454-6612
F: (310) 305-1718
www.columbiamedical.com
Circle # 41
See our ad on page 20

Convaid
2830 California Street
Torrance, CA 90503
P: (310) 618-0111
F: (310) 618-8811
www.convaid.com
Circle # 44
See our ad on page 35

Cycletote, Inc.
517 North Link Lane
Fort Collins, CO 80524
P: (800) 747-2407
F: (970) 482-2402
http://www.cycletote.com
See our ad on page 167

Medi-Fair, Inc.
25 Jefferson Street
Monticello, NY 12701
P: (800) 282-6334 or (845) 342-3003
F: (845) 794-0712
www.medifair.com
Circle # 90
See our ad on page 177

Mr. Mobility
15 Minneakoning Road
Unit 309
Flemington, NJ 08822
P: (800) 555-2909
F: (800) 360-0366
www.mrmobility.com
Circle # 45, 46
See our ad on page 74, 175

Otto Bock Health Care
2 Carlson Parkway North, Suite 100
Minneapolis, MN 55447-4467
P: 763 553 9464
F: 763 519 6153
www.ottobockus.com
Circle # 101
See our ad on page 147

Theradyne Health Care Products, a Div. of Kurt Mfg.
395 Ervin Industrial Drive
Jordan, MN 55352
P: 800-328-4014
F: 952-492-3443
www.theradyne.com &
www.kurt.com
Circle # 129
See our ad on page 125

TELEPHONE EQUIPMENT

Tykris Inc.
PO Box 309
3272 15 Side Road
Campbellville, ON L0P 1B0
P: 905-854-3009
F: 905-854-3012
e-mail: tykris@tykris.com
www.tykris.com

Verizon Center for Customers with Disabilities
280 Locke Drive
Marlboro, MA 01752
P: (800) 974-6006 (V/TTY)
www.verizon.com
Circle # 134
See our ad on page 45

VAN CONVERSION

M.I.T.S. Corporation
11448 N. Main St. Ext.
Glen Rock, PA 17327
PA location - 888-826-7496
Waynesboro, VA - 800-420-6470
www.mitscorp.com
20-30 New/Used Accessible Vans in Stock! Quad driving equipment. Stairlifts & home Wheelchair Lifts Rentals. Leasing & Financing.

Causeway Ford Lincoln Mercury Jeep
Route 72
Manahawkin, NJ 08050
P: (609) 597-8083
F: (609) 597-2089
www.causewaymobility@yahoo.com
Largest Stocking Mobility Dealer in the State of NJ. Causeway can install your new lift, hand controls or any other piece of mobility equipment.

Freedom Motors USA
932 Michigan Avenue
Battle Creek, MI 49014
P: 888-625-6335
F: 606-660-1296
www.freedommotors.com
Circle # 61
See our ad on page 146

General Motors
GM Mobility Assistance Center
PO Box 100
Detroit, MI 48265
P: 800-323-9935
TTY: 800-833-9935
www.gmmobility.com
See our ad on page 43

Liberty Motor Company Inc.
2390 South Service Road West
Oakville, ON L6L 5M9
P: 888-578-8886
F: 905-465-3965
email: sales@libertymotorco.com
www.libertymotorco.com
Circle # 83
See our ad on page 121

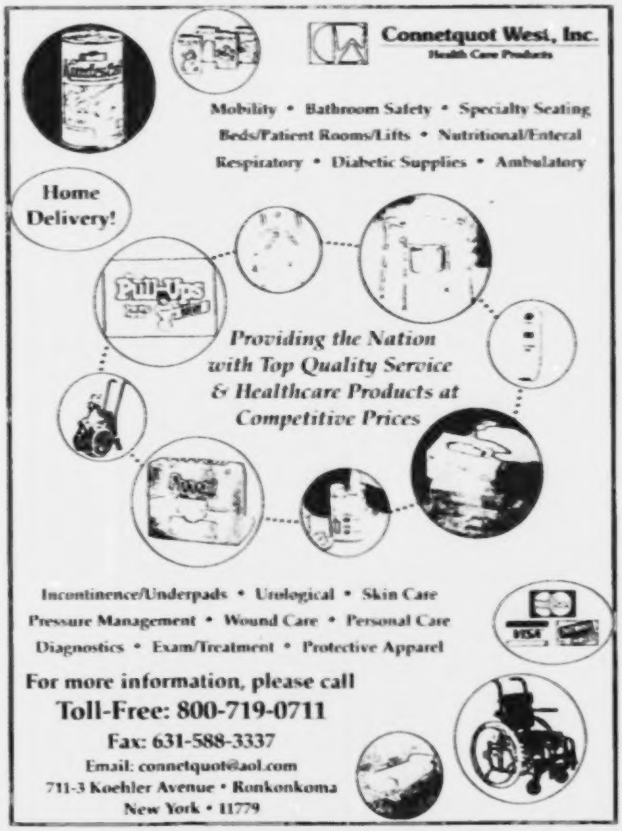
Monmouth Vans, Access & Mobility Equipment
5105 Routes 33/34
Farmingdale, NJ 07727
P: (800)221-0034
F: (732)919-0256
e-mail:monmouthvans.com
www.monmouthvans.com

Motion Automotive Specialty
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com

Performance Vans/Mobility Services
1549 Gateway Blvd
Woodbury, NJ 08096
P:800-929-1207
F: 856-853-8341
e-mail: spvanguy@aol.com
www.performancevan.com

Ride-Away Corp.
51 Wentworth Avenue
Londonderry, NH 03053
P: (888) Ride-Away
F: (603) 432-1549
www.ride-away.com
Other locations include N. Attleboro, MA, E. Hartford, CT and Essex Junction, VT

View Point Mobility
5121E. ML Avenue Suite B40
Kalamazoo, MI 49048
P: 877-368-6022
F: 616-344-5649
www.viewpointmobility.com
Circle # 135
See our ad on page 76



Connetquot West, Inc.
Health Care Products

Mobility • Bathroom Safety • Specialty Seating
Beds/Patient Rooms/Lifts • Nutritional/Enteral
Respiratory • Diabetic Supplies • Ambulatory

Home Delivery!

Providing the Nation with Top Quality Service & Healthcare Products at Competitive Prices

Incontinence/Underpads • Urological • Skin Care
Pressure Management • Wound Care • Personal Care
Diagnostics • Exam/Treatment • Protective Apparel

For more information, please call
Toll-Free: 800-719-0711
Fax: 631-588-3337
Email: connetquot@aol.com
711-3 Koehler Avenue • Ronkonkoma
New York • 11779

Circle #42 or visit www.eparent.com/adinfo

Loneliness shouldn't be a side effect of your child's disability.

At Cotting School, boys and girls of all ages and abilities receive countless opportunities to make friends . . . in the classroom, on a field trip, during basketball practice or in physical therapy. As self-esteem increases with each new friendship, talent and personality shine.

OPENINGS FOR YOUNG PEOPLE FOR 2002 – 2003
NEW POSTGRADUATE RESIDENTIAL PROGRAM NOW OPEN

Cotting School—
where your child belongs.

For information or a tour, please call
Janine Brown-Smith at (781) 862-7323.
www.cotting.org www.cottinghopehouse.org

Cotting
SCHOOL

Cotting School is a 766-approved day school in Lexington, MA for children and youth ages 3-22 with physical, communication, and other challenges to learning.

Circle #47 or visit www.eparent.com/adinfo

VAN RENTAL

Action Mobility Products & Svcs.
1925 10th Avenue North Lake Worth, FL 33461
P: (561) 582-6500
F: (561) 582-2921
Drop Floor Mini Vans
www.actionmobilityproducts.com

Ride-Away Corp.
51 Wentworth Avenue
Londonderry, NH 03053
P: (888) Ride-Away
F: (603) 432-1549
www.ride-away.com
Other locations include N. Attleboro, MA, E. Hartford, CT and Essex Junction, VT

Wheelchair Getaways, Inc.
P.O. Box 605
Versailles, KY 40383
P: 859-873-4973 800-642-2042
F: 859-873-8039
www.wheelchairgetaways.com
Circle # 137
See our ad on page 70

VANS

Freedom Motors USA
932 Michigan Avenue
Battle Creek, MI 49014
P: 888-625-6335
F: 606-660-1296
www.freedommotors.com
Circle # 61
See our ad on page 166

General Motors
GM Mobility Assistance Center
PO Box 100
Detroit, MI 48265
P: 800-323-9935
TTY: 800-833-9935
www.gmmobility.com
See our ad on page 43

Liberty Motor Company Inc.
2390 South Service Road West
Oakville, ON L6L 5M9
P: 888-578-8886
F: 905-465-3965
email: sales@libertymotorco.com
www.libertymotorco.com
Circle # 83
See our ad on page 121

Ride-Away Corp.
51 Wentworth Avenue
Londonderry, NH 03053
P: (888) Ride-Away
F: (603) 432-1549
www.ride-away.com
Other locations include N. Attleboro, MA, E. Hartford, CT and Essex Junction, VT

WALKING AIDS

Mobility Research
2209 West First Street, Suite 105
Tempe, AZ 85281
P: (480) 829-1727
F: (480) 829-0737
www.litegait.com
Circle # 93
See our ad on page 169

Mr. Mobility
15 Minneakoning Road
Unit 309
Flemington, NJ 08822
P: (800) 555-2909
F: (800) 360-0366
www.mrmobility.com
Circle # 45, 46
See our ad on page 74, 175

Mulholland Positioning System
215 No. 12th St., Box 391
Santa Paula, CA 93061
P: 800-543-4769
F: 805-933-1082
e-mail: customer_service@mulhollandinc.com
Circle # 94, 95
See our ad on page 169, 181

Otto Bock Health Care
2 Carlson Parkway North, Suite 100
Minneapolis, MN 55447-4467
P: 763.553.9464
F: 763.519.6153
www.ottobockus.com
Circle # 101
See our ad on page 147

Snug Seat
12801 E. Independence Blvd.
Stallings, NC 28105
P: 1-800-336-7684
F: 704-882-0751
www.snugseat.com
Circle # 118
See our ad on page 5

WHEELCHAIR ACCESSORIES

Bodypoint Design, Inc.
558 First Avenue South Suite 300
Seattle, WA 98104
P: (800) 547-5716
F: (206) 405-4556
www.bodypoint.com
Circle # 32, 33, 34
See our ad on page 99, 148, 175

Theradyne Health Care Products, a Div. of Kurt Mfg.
395 Ervin Industrial Drive
Jordan, MN 55352
P: 800-328-4014
F: 952-492-3443
www.theradyne.com & www.kurt.com
Circle # 129
See our ad on page 125

Are you tired of fighting for your child's medical insurance benefits?

SNAP will help you understand your policy and problem-solve your insurance nightmares.

Whether you need estate planning, medical insurance advocacy, or legal and other referrals, SNAP—Special Needs Advocate for Parents—can help. We provide:

Medical insurance problem solving

Referrals to educational advocates, support groups and others

Special needs estate planning through seminars and consultations with experts in the field

A directory of attorneys with expertise in special needs practice

Our complimentary Info Kit has full details, plus a copy of our latest *SNAP Report* newsletter, a handy resources magnet and more.

Call for your complimentary SNAP Info Kit:
1-888-310-9889
Or for more information, visit our Web site:
www.snapinfo.org

SNAP
SPECIAL NEEDS ADVOCATE FOR PARENTS

Special Needs Advocate for Parents is a not-for-profit public benefit corporation pursuant to IRC§501(c)(3).

Circle #117or visit www.eparent.com/adinfo

PRODUCT & SERVICES DIRECTORY

WHEELCHAIR, POWERED

Permobil, Inc.
6961 Eastgate Blvd., Lebanon, TN 37090
P: 1.800.736.0925, F: 1.800.231.3256
www.permobil.com
Manufacturing in Sweden since 1968, Permobil continues to develop the most durable and technically sophisticated power wheelchairs in the world. Available with a variety of seating choices, Permobil chairs are long lasting and offer a wide selection of features that can be customized to fit the individual's needs.
Circle # 106
See our ad on page 19

WHEELCHAIRS ACCESSORIES

Convaid
2830 California Street
Torrance, CA 90503
P: (310) 618-0111
F: (310) 618-8811
www.convaid.com
Circle # 44
See our ad on page 35

Freedom Designs Inc.
2241 Madera Road
Simi Valley, CA 93065
P: (800) 331-8551 or (805) 582-0077
F: (805) 832-1473
Circle # 60
See our ad on page 75

WHEELCHAIRS, MANUAL

Columbia Medical Mfg. Corp.
PO Box 633
Pacific Palisades, CA 90272
P: (800) 454-6612
F: (310) 305-1718
www.columbiamedical.com
Circle # 41
See our ad on page 20

Convaid
2830 California Street
Torrance, CA 90503
P: (310) 618-0111
F: (310) 618-8811
www.convaid.com
Circle # 44
See our ad on page 35

Deming Design
1090 Cobblestone Drive
Pensacola, FL 32514
P: (850) 478-5765
F: (850) 476-3361
email: kmdeming@aol.com
www.beachwheelchair.com

Freedom Designs Inc.
2241 Madera Road
Simi Valley, CA 93065
P: (800) 331-8551 or (805) 582-0077
F: (805) 832-1473
Circle # 60
See our ad on page 75

Send us your child's photo, essay or artwork!

EP is always looking for submissions for our monthly *Children's Page* and *Familiar Faces* Columns. Send to: Exceptional Parent

65 East Route 4, River Edge, NJ 07661

Invacare Corporation
PO Box 4028
Elyria, OH 44036-2125
(800) 333-6900
e-mail: info@invacare.com
www.invacare.com
Invacare Corporation is the global leader in the manufacture and distribution of innovative medical products which promote recovery and active lifestyles.

Medi-Fair, Inc.
25 Jefferson Street
Monticello, NY 12701
P: (800) 282-6334 or (845) 342-3003
F: (845) 794-0712
www.medifair.com
Circle # 90
See our ad on page 177

Theradyne Health Care Products, a Div. of Kurt Mfg.
395 Ervin Industrial Drive
Jordan, MN 55352
P: 800-328-4014
F: 952-492-3443
www.theradyne.com & www.kurt.com
Circle # 129
See our ad on page 125

Help is just a phone call away...

Are you looking for appropriate services for yourself, a loved one or a client with developmental disabilities?
Do you need information on religious services and materials?

Bethesda's National Christian Resource Center can help! The NCRC offers:

- Lists of support services in specified geographic areas
- Referrals to advocacy and support groups
- Information on and referrals to special religious education programs
- Religious materials and other resources

Bethesda

Lutheran Homes and Services, Inc.
700 Hoffmann Dr.
Waterotwn, WI 53094

www.blhs.org
1.800.369.4636, ext. 418

Circle #29 or visit www.eparent.com/adinfo

PATHFINDER VILLAGE

Specializing in Down Syndrome

Pathfinder Village is a warm, friendly community in the rolling hills of Central New York. Here children and adults who have Down syndrome realize success as they work in the community, go to school, and take part in recreation & social programs.

Pathfinder Village offers:

- **10 nurturing family homes**
- **a dedicated & caring staff**
- **year-long school with teen vocational program**
- **on-site nursing staff**
- **outreach services at the Kennedy • Willis Center on Down Syndrome**
- **a history in human services dating to 1922**

As our residents grow in independence, they build lasting friendships, become partners in the world, and take in all that life has to offer.

PATHFINDER VILLAGE
3 Chenango Road
Edmeston, NY 13335-2314

Call 607-965-8377 or visit www.pathfindervillage.org

Circle #102 or visit www.eparent.com/adinfo

PRODUCT & SERVICES DIRECTORY

WHEELCHAIRS, POWERED

Global Power Systems, Inc.
2703 Commado Ct.
Fort Wayne, IN 46808
P: 800-554-8044
F: 219-482-4866
www.globalpowersystems.com
Pediatric "powered" wheelchair folds in seconds, light weight approximately 55 lbs., built in growth capabilities and easy to use, fully programmable electronics.
Circle # 64
See our ad on page 107

Harmar Mobility
2075 47th Street
Sarasota, FL 34234
P: 800-833-0478
F: 941-360-1937
www.harmar.com
Circle # 70
See our ad on page 173

Invacare Corporation
PO Box 4028
Elyria, OH 44036-2125
(800) 333-6900
e-mail: info@invacare.com
www.invacare.com
Invacare Corporation is the global leader in the manufacture and distribution of innovative medical products which promote recovery and active lifestyles.

Medi-Fair, Inc.
25 Jefferson Street
Monticello, NY 12701
P: (800) 282-6334 or (845) 342-3003
F: (845) 794-0712
www.medifair.com
Circle # 90
See our ad on page 177

Mr. Mobility
15 Minneakoning Road
Unit 309
Flemington, NJ 08822
P: (800) 555-2909
F: (800) 360-0366
www.mrmobility.com
Circle # 45, 46
See our ad on page 74, 175

Quantum™ Dynamo™/Dynamo ATS
Active-Trac Suspension available
Turning radius as low as 16"
15" Seat-to-floor height
www.quantumrehab.com
Circle # 108
See our ad on page 101

Theradyne Health Care Products, a Div. of Kurt Mfg.
395 Ervin Industrial Drive
Jordan, MN 55352
P: 800-328-4014
F: 952-492-3443
www.theradyne.com &
www.kurt.com
Circle # 129
See our ad on page 125

"School" brings special challenges for a child with special needs

With over 40 years of assisting the child with special needs and his/her family we can offer:

- **Preschool Programs for the Child, age 3 to 5 with:**
  Mild to Profound Developmental Delays, Sensory and Communication Delays, and Hearing Impairments
- **School Program for the Child, age 3 to 21 with:**
  Multiple Developmental and/or Medical Needs including Acquired Brain Injury
- **We Offer All Students:**
  Small Classes with 210-day Caldenar
  On-site Nursing Services
  Assistive Technology
  Customized Adapted Equipment
  Augmentative Communication
- **We Offer All Families:** *(enrollment in school not necessary)*
  Comprehensive Audiological Services
  Family Support Resources (toy library, parent networking & referral, and more)

Call (203) 386-2743 for more information

FEROLETO Children's Development Ctr.
95 Merritt Blvd., Trumbull, CT 06611
www.stvincentsspecialneeds.org

St.Vincent's
Special Needs Services

Circle #121 or visit www.eparent.com/adinfo

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

ECZEMA
TOUGH WORD

TOUGH
DISEASE

For information contact: Inflammatory Skin Disease Institute at (757) 223-0795 ExDirISDI@aol.com
Or
American Academy of Dermatology
(847) 330-0230

Circle #1

Natural Access
Expand your horizons with the Landeez All-Terrain Wheelchair!

Rolls easily over sand, snow, gravel, and uneven terrain, so you can enjoy the outdoors

For more info 800-411-7789 or visit
www.landeez.com

Circle #2

DISCOVER
FREEDOM Concepts Inc.

FREEDOM
"GIVE US A NEED, WE WILL FIND THE CONCEPT!"
FREEDOM CONCEPTS INC.
P.O. Box 45117 RPO Regent Ave West
Winnipeg, Manitoba, Canada R2C 5C7
PHONE: 1-800-661-9915 FAX: 204-654-1149
www.freedomconcepts.com

Circle #3

The Hanen Centre®
HELPING CHILDREN COMMUNICATE

The Hanen Centre helps young children with language delays communicate to the best of their abilities through innovative programs and practical learning resources for parents and professionals. Our user-friendly, richly illustrated guidebooks and videos provide practical information on how to help children develop their language and social-interaction skills in everyday situations.

The Hanen Centre
P.O. Box 1213
Buffalo, NY 14240-1213
Tel: (416) 921-1073
Fax: 1-800-380-3355
email: info@hanen.org
www.hanen.org

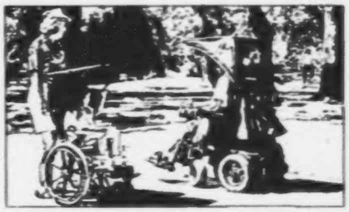
Circle #4

- Stain Proof
- Water Repellent
- Washable
- Adult-Children Sizes

STAIN-BUSTING BIBS !

Grow With Me® Creations
14236 Wade Ave, Hartville, OH 44632
1-800-850-1889
email: bibs@growwithme.com
website: www.growwithme.com

Circle #5



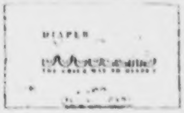
DIESTCO MFG. CORP.

All kinds of great stuff is available for wheelchairs! Products include canopies for protection from rain or sun, backpacks, cupholders, threshold ramps, laptrays, leg covers, and much more. Call **Diestco Mfg. Corp.** at: 1-800-795-2392, or visit www.diestco.com.

Circle #6

BEST COPY AVAILABLE

Diaper Doublers™



Diaper Doublers inserts that make cloth or disposable diapers more efficient, pulling moisture away from a child's tender skin.

- Trim & Comfortable
- Overnight Protection
- Absorbency without Bulk
- Latex-Free for Sensitive Skin

www.DiaperDoubler.com
1-800-335-4434
Toll-Free Phone Orders
"The Drier Way to Diaper"™

Circle #7

Access Fair™

Inclusion Through Literature **Books About Children w/ Disabilities Real Life Stories of Inclusion.**
Read about one heroine in the Exceptional Parent, November, 2000 issue, "Seeing Past a Child's disability" by L. O'Neill

FREE CATALOG
PO Box 21325, Cols, OH 43221-0325
Tel. (614) 486-4441, Fax (614) 486-6532
email: rigsbee@accessfair.com
http://www.accessfair.com

Circle #8

Now he has a place for everything like everyone else.

It's unique ball-joint movements and sturdy support put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, and pencils. And when it's time for transfers, the entire desktop swings down to the side.

1-800-4 MYDESC
www.mydesc.com
Santa Clara, CA 95056

Circle #9

VITAL ID
INFORMATION SAVES LIVES

Your accurate emergency information when you need it most

Vital ID stores your entire family's vital info at our secure website, providing authorized emergency personnel only with speedy access to important identification and medical information.

www.VitalID.com
(800)558-6021

Circle #10

WOODBINE HOUSE CATALOG

NEW BOOKS on Down syndrome and autism!

WOODBINE HOUSE
www.woodbinehouse.com

The new Spring 2002 Woodbine House catalog features our **Special-Needs Collection**, 60 books on a wide variety of disability topics for parents, children, teachers, therapists, and health care providers.

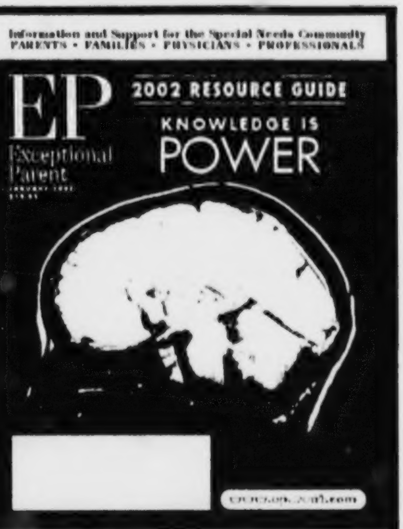
**For a FREE catalog, contact:
Woodbine House at 800-843-7323**
Circle #11

EXCEPTIONAL PARENT

Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores All Across America. Every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books. $4.95 Cover Price.

Circle #12


Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS
EP
Exceptional Parent
2002 RESOURCE GUIDE
KNOWLEDGE IS
POWER

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/handling). To order, call 1-800-535-1910.

MARKETPLACE

Affordable independence in the great outdoors!

De Bug chairs bring you back to nature: beaches, woods... anywhere... hassle-free!
Call today for your free brochure:
850-478-5765
850-476-3361 fax
Deming Design Inc.
www.beachwheelchair.com
kmdeming@aol.com

BOOKS, AUDIO/VIDEO EDUCATIONAL MATERIAL

GUIDE TO
SUMMER CAMPS
AND
SUMMER SCHOOLS
28th Edition Now Available
ISBN 0-87558-146-3 $27

Recreation, academics, travel and special interest: extensively indexed listings of more than 1000 residential programs worldwide featuring programs and facilities serving special needs youth.

Make the right choice for your child this summer. Order today.

Visit www.portersargent.com
or call 1-800-342-7470

PORTER SARGENT PUBLISHERS, INC.
300 Bedford St., Ste. 213
Manchester, NH 03101
Fax: 603-669-7945

THE DIRECTORY FOR
EXCEPTIONAL CHILDREN
14th Edition Now Available
ISBN 0-87558-141-2 $75

Provides critical details on 2500 schools, programs and facilities nationwide, serving youth with developmental, emotional, physical and medical disabilities.

An invaluable aid for parents and professionals seeking the optimal environment for special-needs children.

Visit www.portersargent.com
or call 1-800-342-7470

PORTER SARGENT PUBLISHERS, INC.
300 Bedford St., Ste. 213
Manchester, NH 03101
Fax: 603-669-7945

DIFFERENT ROADS TO LEARNING
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

BICYCLE TRAILER

Bicycle trailer

Blue Sky Cycle Carts

- Low profile insures maximum stability
- Comfortable cloth-covered bucket seat
- 5-Point safety harness prevents slipping
- Seats child or adult (4ft. minimum height)
- Carries up to 200 lbs. weight
- Large, easy-rolling 24-inch pneumatic tires

P.O. Box 5788, Bend, OR 97708
For a free catalog call: 1-800-669-1753
www.blueskycyclecarts.com

CAMP GUIDE 2002

RESOURCE FOR CHILDREN WITH SPECIAL NEEDS, INC.
200 Park Avenue South, Suite 816
New York, NY 10003
(212) 677-4650
Fax: (212) 254-4070
www.resourcesnyc.org
Complete up-to-date Guide to New York City day camps and summer programs in the northeast for children with special needs. Order direct from Resources, Dept. PR1 to address above. Send check for $22 + $5.00 postage/handling. Annual Camp Fair will be on Feb. 3, 2002 in NYC. Call number above for further details.

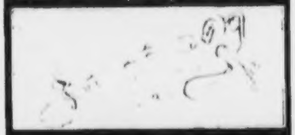
ATTORNEY

ATTORNEY RICHARD GOTTESMAN
(800)295-1107
gottesman@law.com
Cerebral Palsy, Brachial Plexus/Erb's Palsy and Childbirth Injuries

BEACH SWIMMING POOL

TIRALO™
FLOATING BEACH CHAIR

Call now: (360) 796-3197



www.oasisllc.com

CLOTHING

David's Collection

Fashionable & durable vinyl backed terry cloth **BIBS** made to order
Choice of pattern & style

Sm. $13.00
Md. $15.00
Lg. $17.00
plus s&h $3.50

NEW
Vinyl Backed
Tie Bandanas
$6.50 plus s&h

CALL DAVID'S MOM
for more info — ordering
410-668-0068

Visit: www.DavidsCollection.com

CYCLES

Cycles for Virtually Every Special Need & Age

Amputations, Cerebral Palsy, Spina Bifida, Visual Impairments/ Blindness, and many others

You Can Even Earn Your Own Cycle!
806-894-5700 FAX: 806-894-1238

Check us out on the Web...
http://www.rocknrollcycles.com

SEATING & POSITIONING

DESIGNED WITH CHILDREN IN MIND
Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Leckey products feature lighter mobile bases, more adjustable components, peer level positioning, child friendly positioning straps and playful colors.

- Freestander
- Totstander
- Easy Seat
- Advance Bath Chair
- Toilet/Shower Chair
- Basic Bath Support
- Pronestander

Call Sammons Preston today at 1-800-323-5547 for a complete Leckey® brochure.

INCONTINENCE

ARC HOME HEALTH PRODUCTS
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so. Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider. Resource information: www.medmarket.com
e-mail: info@archhp

Ask about our Youth Brief sample pack. Only $5.99!

HDIS

FREE CATALOG

Call Today!
1-800-2MY-HOME™
(1-800-269-4663)

RESOURCES

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/ handling). To order, call 1-800-535-1910.

MARKETPLACE

EQUIPMENT DEALERS

American
Discount Medical

Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

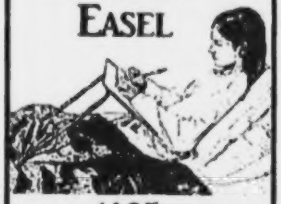
Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

FURNITURE

THE EASY BED EASEL



Only $14.95 *plus S&H*

Endorsed by Children's Hospitals, Child Life Specialists and Special Needs Professionals

Smyth Company, Inc.
TOLL FREE **1-877-906-9124**
www.smythcoinc.com

FREE INFORMATION RESOURCE

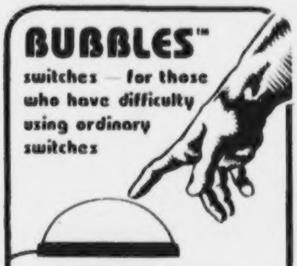
TURTLE BOOKS

JASON & NORDIC
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg,
PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

SWITCHES

BUBBLES™

switches — for those who have difficulty using ordinary switches



Convenient dome shape! Can be set so the hand only needs to pass near the switch!

Also ask about our touch-sensitive switch pads to mount directly on hand splints!

EQUAL ACCESS
COMPUTER TECHNOLOGY, INC.
222 Grant Way
Lancaster, MA 01523
978-466-9191 eact@world.std.com

WORK AT HOME

CAREER STEP
Train at home to work at tome: Career Step offers quality training in medical transcription, a rewarding career that allows you the freedom of working from home. Free Information 1-800-411-7073, ext. 1201.
www.careerstep.com

MONITORING SYSTEM

CARE ELECTRONICS INC.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price
Call for FREE CATALOG

VAN CONVERSION DEALERS

MASSACHUSETTS

MOTION AUTOMOTIVE SPECIALTY
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—
Day, Week or Month.

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

CAMPHILL SPECIAL SCHOOL

The only Camphill Children's Village for developmentally-disabled children in North America.

- school & residential program (ages 4 - 19); pre-vocational program
  —***also openings in Integrated Kindergarten***—
- wide variety of therapies; on-campus medical care staff & facility
- cultural activities-music, art, drama, festivals
- beautiful homes with permanent house-parent families

We also have openings for young people to explore work with developmentally-disabled children in a community setting.

1784 Fairview Road, Glenmoore, PA 19343
610-469-9236; Fax: 610-469-9758; e-mail: BvrRn@aol.com
website: www.beaverrun.org

Circle #35 or visit www.eparent.com/adinfo

CHILDREN'S CARE
HOSPITAL & SCHOOL
For Children with Disabilities and Their Families

CHILDREN'S CARE HOSPITAL & SCHOOL *(formerly Crippled Children's Hospital & School)* is a private, nonprofit facility serving over 1700 children and families each year. Individualized, family-centered programs available through day and summer school, outpatient, outreach, or residence. Accredited pediatric rehabilitation program now offered.

Contact:
Aaron Wimmer, ADMISSIONS LIAISON
Children's Care Hospital & School
2501 West 26th Street • Sioux Falls, SD 57105-2498
(605) 782-2300 or (800) 584-9294, Ext. 2379

Circle #37 or visit www.eparent.com/adinfo

TO ADVERTISE IN MARKETPLACE CONTACT:

Barbara Nastro

TEL: (908) 534-6366 FAX: (908) 534-6941

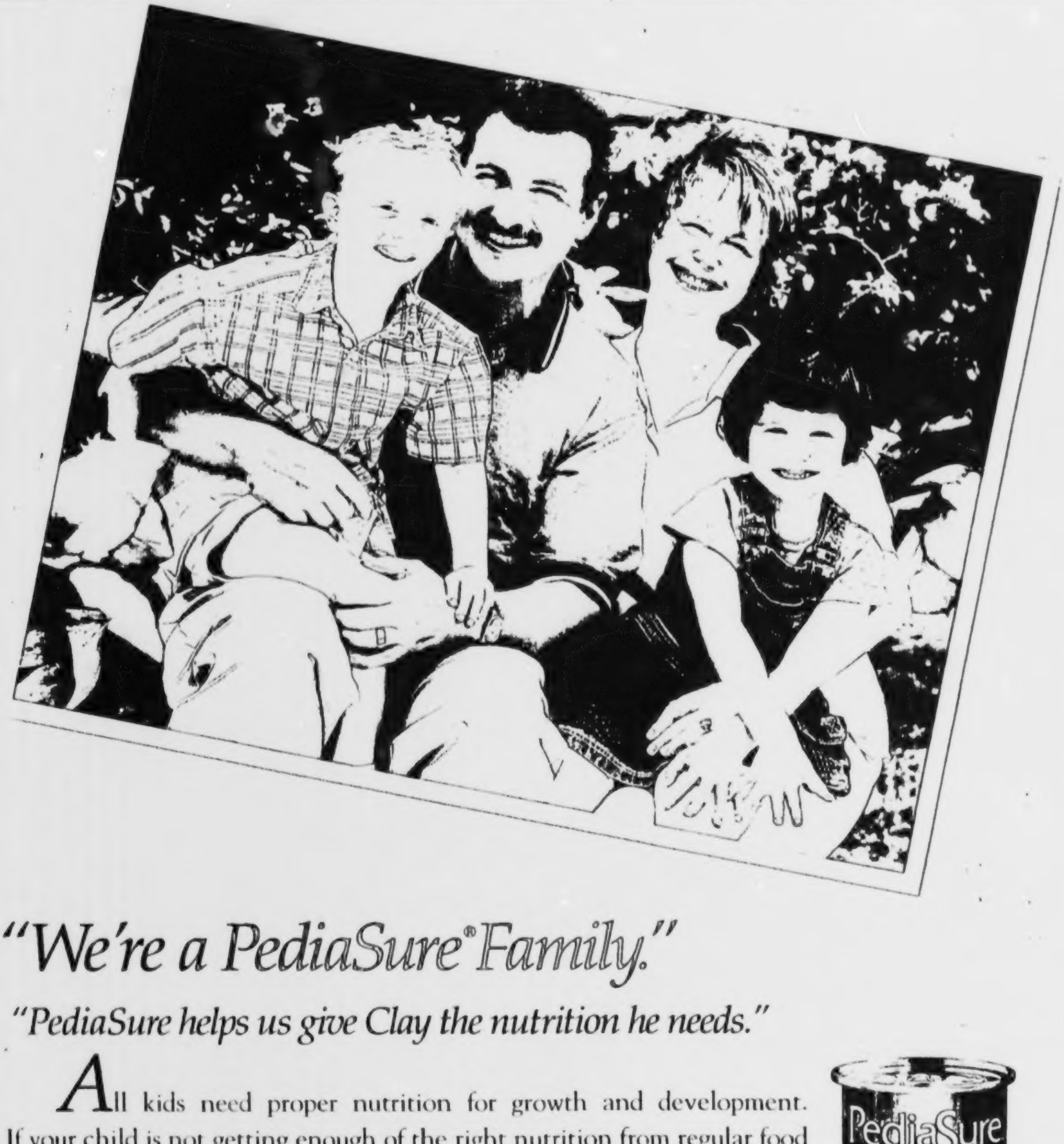
2002 EP Editorial Calendar

In an age of chronic information overload, EP is dedicated to bringing its readers the crucial information they need. In addition to regular columns and features such as Search and Respond and Familiar Faces, EP will include educational programs such as the continuing series on oral health. And every month, EP includes a special section on a specific topic*:

	Early Childhood—From fetal ultrasounds through the routine checkups of toddlerhood, there are many points for early diagnosis and treatment of special needs.
MARCH	**Life Planning**—Financial and estate planning are only part of ensuring life-long care of your dependent with a disability. **Summer Fun**—Choosing camps and other summer programs. Tips for fun, accessible travel that everyone can enjoy.
	Special Advertising Section: Schools, Camps and Residences
APRIL	**Medical Research Update**—The latest theories and treatments in several areas. Reviewing clinical trials that are seeking participants.
	Special Advertising Section: Mobility
MAY	**Transitioning**—A life-long concern, including education, living arrangements and sociopsychobiological issues.
	Special Advertising Section: Van Conversion Dealers
	Technology—Reporting on new trends, products and possibilities. Augmentative and alternative communication devices, software programs, adaptive equipment and more.
JULY	**Teenagers and Young Adults**—How to cope with significant personality changes, mood swings and the need for independence. How to maintain your love and support for your teenagers when you want to tear your hair out!
AUGUST	**Healthcare**—Current information on treatments, procedures and research. Updates on changes in healthcare legislation. Managed healthcare, health insurance, Medicaid and other funding sources.
SEPTEMBER	**Education**—Parents and educational professionals share experiences and offer suggestions. Achieving optimal services for your student in a time of tight budgets and resistance to change.
	Special Advertising Section: Schools, Camps and Residences
	Toys, Games and Play—Toys for fun, learning and comfort. Adaptive sports and fitness. Play and creativity. Issue for 2002 World Congress & Exposition on Disabilities.
NOVEMBER	**Stress Management**—Covers sources of stress and how to minimize it. Some coverage of complementary and alternative therapies.
DECEMBER	**Family and Community**—Reaching out to others; community involvement; participation in religious and spiritual activities. Direct Support Professional (DSP) forum.

* Subject To Change

Clay, Danny, Robin and Danielle Wagner live in Fort Lauderdale, Florida. Clay is autistic and has a seizure disorder.



"We're a PediaSure® Family."

"PediaSure helps us give Clay the nutrition he needs."

All kids need proper nutrition for growth and development. If your child is not getting enough of the right nutrition from regular food or has special feeding needs, ask your doctor about the complete, balanced nutrition of PediaSure. It's specially formulated to provide children with proper amounts of protein, fat, carbohydrate, vitamins and minerals. Available in your local supermarket, drug or discount store.

PediaSure
Pediatrician Recommended
Lactose Free

Available through WIC®*

*If your child has special dietary needs, check with your physician or local WIC clinic to see if your child is eligible to receive PediaSure through the WIC program. WIC is a registered trademark of the U.S. Dept. of Agriculture.

© 2001 Abbott Laboratories

Circle #112 or visit www.eparent.com/adinfo

A Better Bedtime Story

The Vail Enclosed Bed

Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peac of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for you child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt. Plus, we provide assistance in obtaining insurance approval.

Available from home health-care products dealers, or direct from th manufacturer.

For a FREE catalog, call:
1-800-235-VAIL

BEST COPY AVAILABLE

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard

Ask about Our Decorator Accessories.

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

Sheri Wittmer
Sandusky, Ohio

Vail Meadows Therapeutic Riding Center

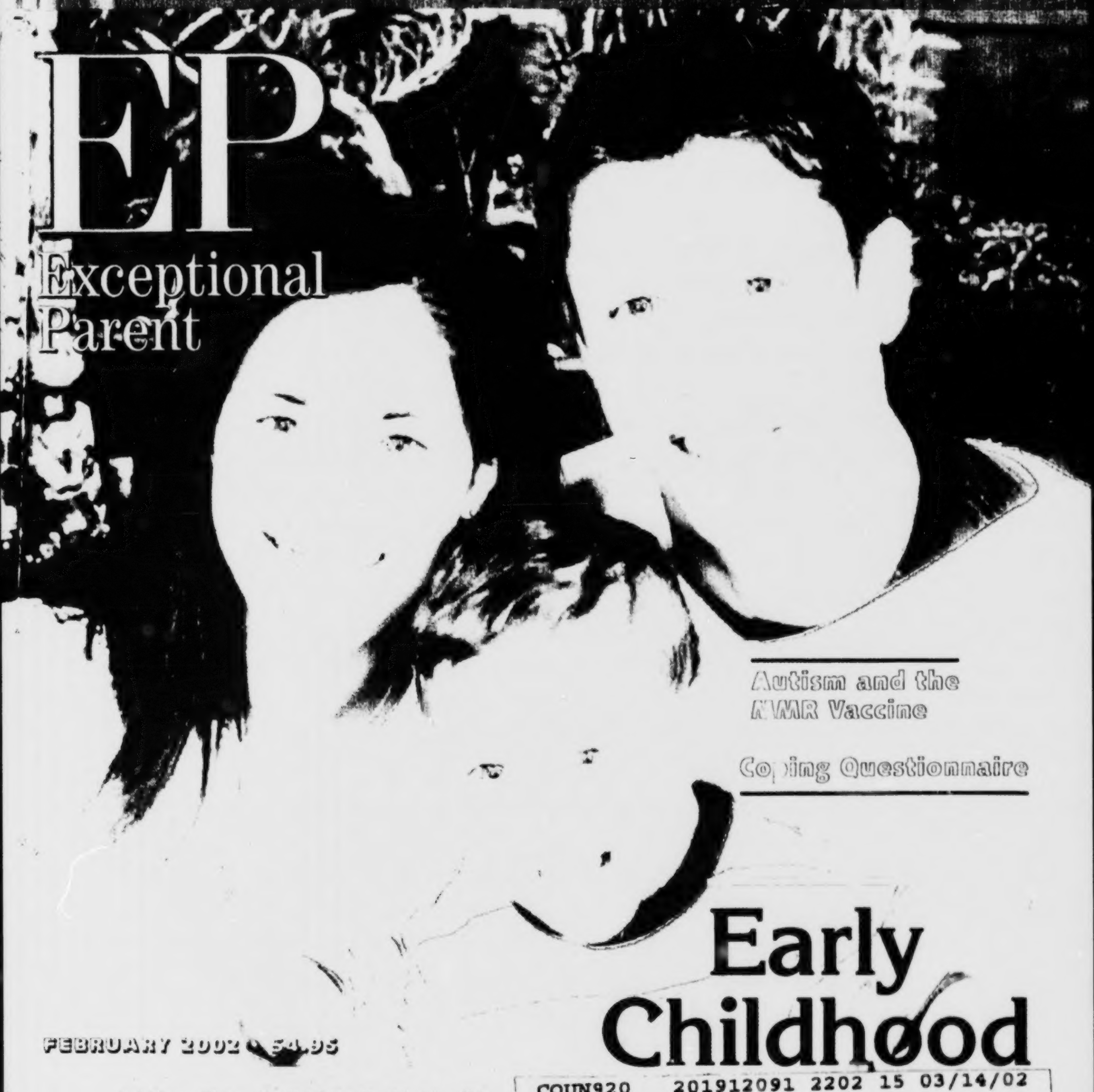
Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for challenged riders.

Circle #133 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent



Autism and the MMR Vaccine

Coping Questionnaire

Early Childhood

FEBRUARY 2002 • $4.95

******************5-DIGIT 20191
NATIONAL CLEARINGHOUSE FOR PROFESSIONS BI
COUNCIL FOR EXCEPTIONAL CHILDREN
1920 ASSOCIATION DR S97 P4
RESTON VA 20191-1500

COUN920 201912091 2202 15 03/14/02
COUNCIL FOR EXCEPTIONAL CHILDREN
1110 N GLEBE RD STE 300
ARLINGTON VA 22201-4795

R=6727

www.eparent.com

BEST COPY AVAILABLE

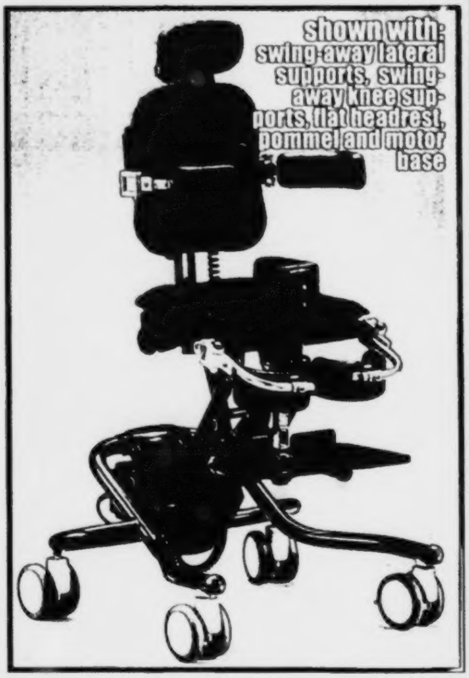
Informed Parents

Where Parents Keep Up To Date On Products For Their Children's Special Needs

Introducing

WOMBAT ACTIVITY CHAIR

FUN Fact
the Wombat puts your child where the action is


shown with: swing-away lateral supports, swing-away knee supports, flat headrest, pommel and motor base

With its multiple adjustments in depth, height, and angle, the Wombat is the most versatile activity chair. The smart and flexible design of the Wombat allows for the child to be "where things happen" whether it be on the floor with other children, or at a desk learning, Wombat is your solution.

shown with: tray, swing away knee supports, flat headrest, and motor base

low position

Information

1-800-336-7684

snugseat.com

SNUG SEAT®

Circle #49 or visit www.eparent.com/adinfo

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

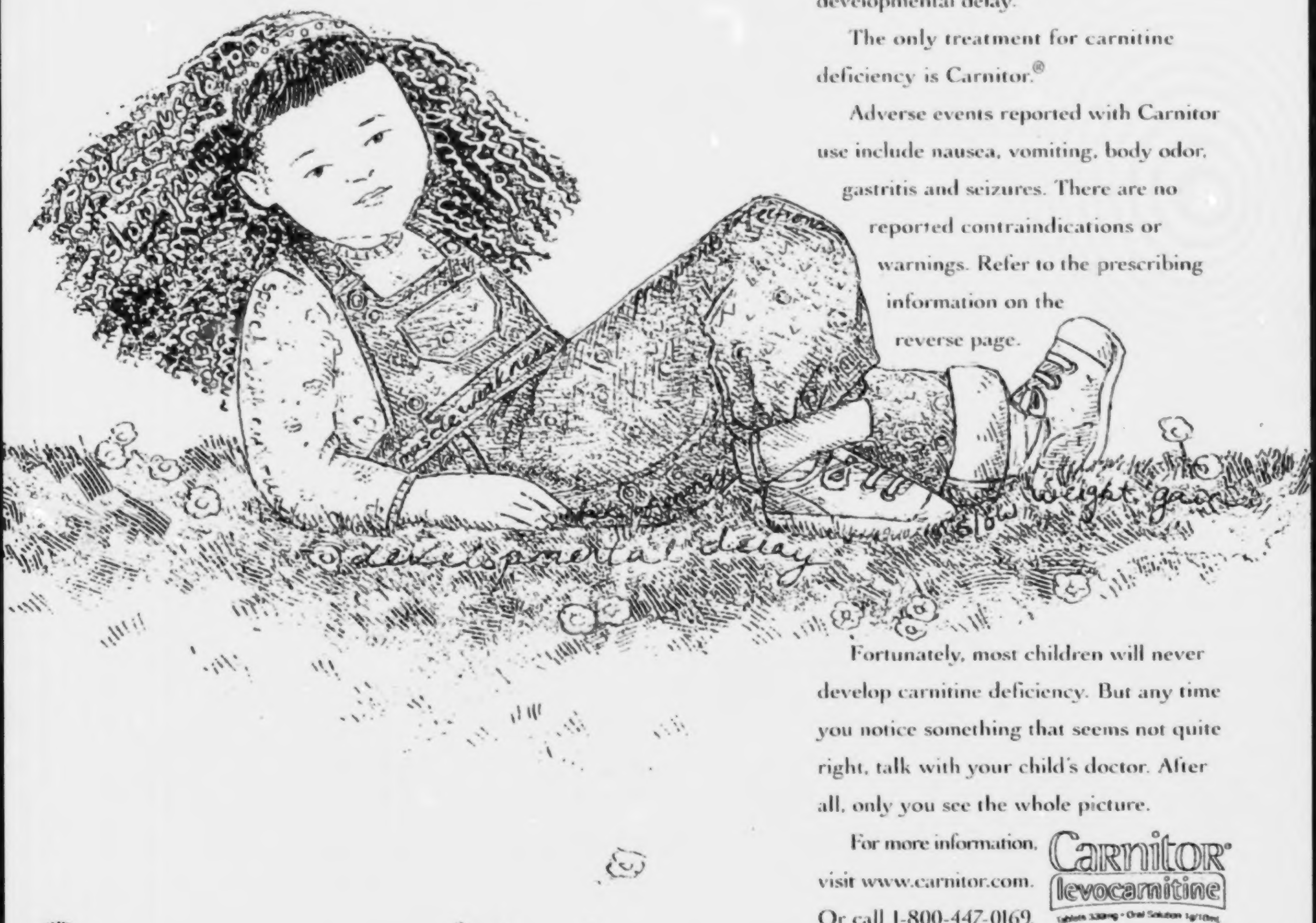
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Circle #48 or visit www.eparent.com/adinfo

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

Independence means different things to different people. For children with bladder or bowel control problems, it could just mean getting through the day dry. That's why something as simple as a change in clothing, can, even in a small way, change a child's way of life.

WHY CHILDREN WHO RELY ON GOODNITES ARE MORE INDEPENDENT.

GoodNites® absorbent underpants can help a child become more independent. With GoodNites, accidents won't become catastrophes. So your child will be able to do more. Plus, because they look like real underwear, kids don't mind wearing them. And since they're easy to pull on and off, they can make a child feel more self-reliant.

GoodNites are available in 3 sizes: 45–65 lbs., 65–85 lbs., and 85–125 lbs. That means finding the size that fits your child will no longer be a problem. Plus they have tear-away sides and they're latex-free.

- *Day and nighttime protection*
- *Latex-free*
- *Tear-away sides for easy removal*
- *Three sizes, to fit kids from 45–125 lbs.*

Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS
45 lb & over

For Better Days.

Imagine your child gaining a little more independence just by a change in clothing. For information on how GoodNites can help, and a free sample offer, please visit us at www.goodnites.com/offer

®Registered trademark of Kimberly-Clark Corporation. ©2000 KCC.

abilities EXPO

Florida
Broward County
Convention Center
March 22-24

New York Metro
New Jersey
Convention Center
April 12-14

Southern California
Long Beach
Convention Center
June 7-9

Greater Cleveland
I-X Center
July 19-21

Chicago Metro
Donald E. Stephens
Convention Center
August 16-18

New England
Bayside Expo Center
September 20-22

Northern California
San Mateo County
Expo Center
November 22-24

Education and
Equipment to
Empower.

Come **sample products** and **talk one-on-one** with service providers. As our guest you can attend **complimentary educational workshops** on everything from better sex to better jobs. Or perhaps you would like to see the power of new technologies in our **Access Ability Pavilion.** There are many options for you at **Abilities Expo.**

For more information please call (800) 385-3085 or (218) 723-9130 outside of the USA.
www.abilitiesexpo.com

abilities EXPO

PRESENT THIS COUPON
FOR FREE ADMISSION

[ADMIT ONE]

Bring coupon to any **2002 Abilities Expo** and save the $5 on-site registration fee.
Coupon must be filled out to be valid and may be photocopied for additional registrants.

NAME: ______________________________

ADDRESS: ______________________________

CITY: ____________ STATE: ______ ZIP: __________

For information call:
(800) 385-3085
(218) 723-9130 (outside USA)

Produced and Managed by:
ADVANSTAR
COMMUNICATIONS

All events are wheelchair accessible.

© 2002 Advanstar Communications Inc. All rights reserved.

Circle #16 or visit www.eparent.com/adinfo

contents

FEBRUARY 2002 • VOLUME 32, ISSUE 2

early childhood

38 **Safety of Your Child with a Disability**
by Cema Mastroleo, MEd, and Wendie H. Abramson, LMSW
Tips on how to teach your child about personal safety.

40 **Early Warning**
"Just a late talker" was a phrase two mothers kept hearing when they questioned their children's lack of verbal ability. Pressing for answers, they discovered the mysterious disorder called verbal apraxia and found out about the importance of early intervention and support.

Dealing with a Parent's Worst Nightmare
by Jeanne Buesser

Evan's Story
by Stacey Abenstein

52 **Effective Social Skills Programming**
by the May Institute, Inc.
Social interactions can often be difficult for children with behavior disorders. With the right information, parents can be proactive in constructing the right social skills program to teach children how to interact appropriately in all the settings of their daily lives.

76 **ORGANIZATIONAL SPOTLIGHT**
Children's Neurobiological Solutions Foundation
by Terry Boisot
Imagine a foundation that supports the collaboration and research of some of the best neuroscientists–to focus not on a disease, but the brain itself.

76 **MEDICAL RESEARCH UPDATE**
Autism and the MMR Vaccine
Some parents believe that there is a link between the MMR vaccine and the incidence of autism. This article reports on the latest research.

Early childhood—a journey of discovery. Copyright ©2002 Laura Dwight

FEATURES

44 **RESEARCH REFLECTIONS**
"Confessions of a Researcher: Blind Alleys, Unintended Consequences and Really BIG Mistakes"
by Jan Blacher, PhD
EP introduces a brand new column contributed by Dr. Jan Blacher, a researcher on family and disability. Starting with this month's installment, Dr. Blacher takes a hard look at the data in the field and what it means for families in their day-to-day lives.

SPECIAL REPORT:

26 **Oral Healthcare for People With Special Needs Part VIII**
The Relationship between Genetic Disorders and Oral Health, Part II: Developmental Anomalies of the Oral Cavity

46 **Coping with Disaster**
by Project Cope
How does your family cope with disaster? Tell us by participating in the Project Cope–EP Family Survey.

54 **Gynecological and Reproductive Services for Teenage and Adult Women with Special Needs**
by Catharine A. Kopac, PhD, GNP
A look at women's healthcare and how people with disabilities are served.

54 **Search & Respond Index 2001**
Topics and dates of reader questions and corresponding replies as they appeared in EP's popular Search & Respond column throughout 2001.

COVER: Cindy and Jeff Grabow are pictured holding their son, Jordan, 2. Jordan loves reading books, bouncing balls and playing with toy cars and trucks. He has a developmental delay of unknown origin.

Cover photo: Copyright ©2002 Laura Dwight

EP
Exceptional Parent

contents

DEPARTMENTS

10 **Editor's Desk**

12 **Letters**

19 **Search & Respond**

24 **What's Happening**
- Autism Fact Sheets Available
- National Arbor Day Foundation Poster Contest
- New AAP Program on Universal Newborn Hearing Screening

26 **Book Notes**
- Courage
- Teaching Playskills to Children with Autism Spectrum Disorder

62 **EP Library**

64 **Legislative Update**

71 **Familiar Faces**

83 **New Products**

84 **Children's Page**
Differences Don't Count
by Jessica Mercola

EDITORIAL MISSION

- To reach out to mothers and fathers of children and young adults who have disabilities and special health-care needs.
- To empower parents and professionals by providing practical information and emotional support.
- To appreciate that parents are the most important experts in the lives of their children.
- To energize parents and professionals.
- To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.

Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy-Ed Corp., dba *Exceptional Parent Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy-Ed Corp. *Exceptional Parent*® is a registered trademark of the Psy-Ed Corp. **Postmaster:** Please send address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *Exceptional Parent*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #1420542. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

Exceptional Parent neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
While hyperbaric oxygen is effective therapy in certain conditions it is currently considered an alternative therapy for CP and other "brain insult" conditions. Readers are advised to discuss the advisability of HBOT with their primary or specialty healthcare providers as well as to study the current literature.
—*Rick Rader, MD*

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

MITCHELL F. BRIN, MD, Vice President, Botox, Allergan, Irvine, CA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics, Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof. Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

HARILYN ROUSSO, ACSW, Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

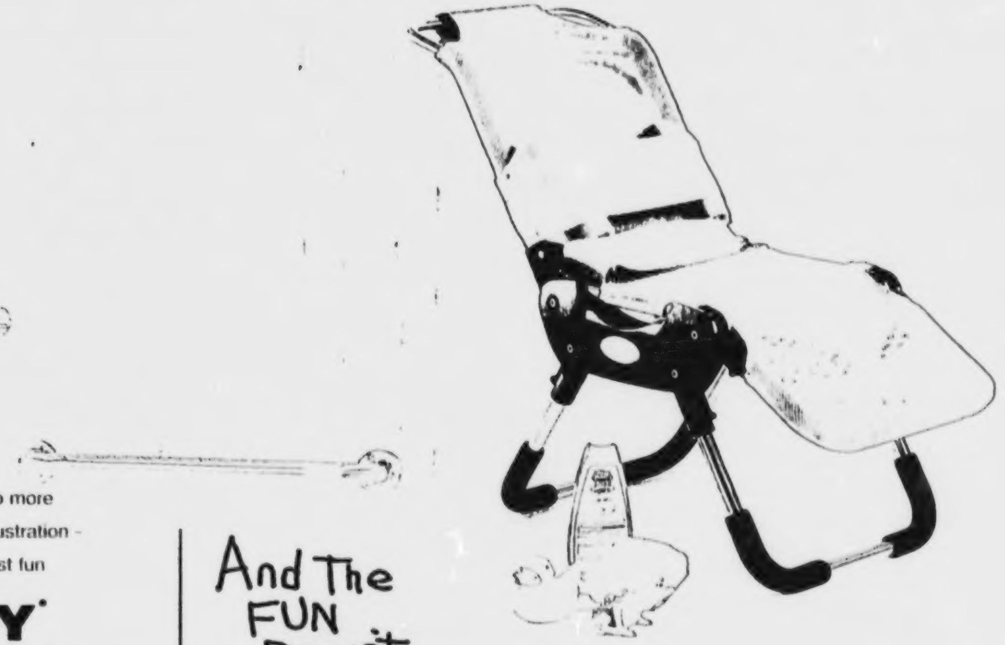
HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

THERESA VARNET, MSW, JD, Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO



no more frustration - just fun

LECKEY®

Advance Bath Chair

New Design

The most extensive height range and adjustable seat angles make bath positioning easy.

Extra-soft mesh material and padded support bars give your child a more comfortable and enjoyable bath time.

Take the Advance Bath Chair from the tub to the shower with the optional trolley

Also available is the Basic Bath Support that provides adjustable positioning angles at a fixed height.

And The FUN Doesn't Stop There

Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Call us today for more information.

- *Lighter mobile bases*
- *More adjustable components*
- *Peer level positioning*
- *Child friendly positioning straps*
- *Playful colors*

Pronestander

Freestander

Totstander

Toilet/Shower Chair

Easy Seat

SAMMONS® PRESTON
AbilityOne

Leckey® products are brought to you exclusively by Sammons Preston®

Start the fun today! Contact your local Sammons Preston distributor or home health dealer for more information.

Or call Sammons Preston at

1-800-323-5547

Circle #47 or visit www.eparent.com/adinfo

THE CENTER FOR CHILDREN • HOSPITAL FOR JOINT DISEASES

Caring for children with
Cerebral Palsy
requires the help of many specialists.

Now you can find them all at
one special place.

The Center for Children is the one place you'll find all the care options you need, with just one concern in mind: your child. By bringing together the resources of the Hospital for Joint Diseases (HJD) and the Rusk Institute of Rehabilitation Medicine (RIRM) of NYU Hospitals Center, we can care for a variety of conditions in one convenient setting. For example, you'll find the widest possible range of treatments for children with cerebral palsy, with in-house specialties including pediatric physiatry, orthopaedics, speech therapy, neurology, neurosurgery, physical and occupational therapy. All in a gentle, kid-friendly environment where there are no white coats, but plenty of color, interaction, toys, games and stimulation. From newborns to 21-year-olds, The Center for Children treats them better. **Call us at 212-598-2330.**

The Center for Children
Hospital for Joint Diseases
301 East 17th Street • New York, NY 10003 • www.jointdiseases.com

For additional comprehensive pediatric services, contact:

NYU Medical Center
NYU Children's Health
866-CHILD-NYU

MOUNT SINAI NYU
HEALTH

Circle #54 or visit www.eparent.com/adinfo

EP

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

EDITOR-IN-CHIEF	Rick Rader, MD
MANAGING EDITOR & VP OF MEDICAL EDUCATION	Fern R. Potvin
EDITORIAL ASSISTANT	Nancy M. Derbyshire
EDITORIAL/MARKETING INTERN	Christina E. Spatz
INFORMATION SYSTEMS COORDINATOR	Dennis Dusevic
RESEARCH ASSISTANT	Susan Jenkins
GRAPHIC CONSULTANT	Dennis Wilkes

PRESIDENT, CEO, & PUBLISHER	Joseph M. Valenzano, Jr.
EXECUTIVE VP/GENERAL MANAGER & ASSOCIATE PUBLISHER	Robert S. D'Angelo
VP BUSINESS DEVELOPMENT & INTERNET PROJECTS	Vanessa B. Ira
VP ORGANIZATION RELATIONS & CONSULTING EDITOR	Bridget M. Lyne
CHIEF FINANCIAL OFFICER	Dolores A. Kinley
AD TRAFFIC MANAGER	Kendra Kelly
SALES COORDINATOR	Doris DeFina
RECEPTIONIST/PUBLIC RELATIONS COORDINATOR	Robyn Sager
ART DIRECTION, DESIGN	Publishers Design Group, Inc. ✉ annpdg@aol.com
PRODUCTION MANAGER/ TRADE SHOW & CONFERENCE MANAGER	Michael Longobardi
EP LIBRARY	Ron Richards (800) 535-1910 ✉ eplibrary@aol.com
WEBMASTER	Ted Doran ✉ webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Jared F. Adams
EASTERN REGION:
(CT, ME, NH, NJ, NY, RI, VT)
✉ jadams@eparent.com
(201) 489-4111,
ext. 211
FAX: (201) 489-0074

Barbara Nastro
SOUTHEAST REGION:
(AL, AR, DC, DE, GA, FL, MD,
MS, NC, PA, SC, VA, WV)
SCHOOLS, CAMPS, RESIDENCES
& CLASSIFIED
✉ nastro@blast.net
(908) 534-6366
FAX: (908) 534-6941

Annabelle and Gabe Jacobson
MIDWEST REGION:
(IA, IL, IN, KS, KY, MI, MN, MO,
NE, ND, OH, OK, SD, TN, WI)
AUTOMOTIVE
THE LYON GROUP
✉ bellyon@megsinet.net
(847) 256-6850
FAX: (847) 256-6819

Larry Battistello
WESTERN REGION:
(AK, AZ, CA, CO, HI, ID, LA, MT,
NM, NV, OR, TX, UT, WA, WY)
Marketing Plus
✉ seeme4ads@aol.com
(760) 320-8797
FAX: (760) 320-9728

Vanessa B. Ira
MASSACHUSETTS &
INTERNET AD SALES
✉ vieprnt@concentric.net
(201) 489-4111, ext. 209
FAX: (201) 489-0074

Jeffrey Yamaguchi
CANADA, AUSTRALIA,
UNITED KINGDOM, &
CUSTOM COMMUNICATIONS
ProMedia Communications, Inc.
✉ ProMedComm@aol.com
(905) 796-7931 ext. 23
FAX: (905) 454-9671

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

PUBLISHING & EDITORIAL OFFICE
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

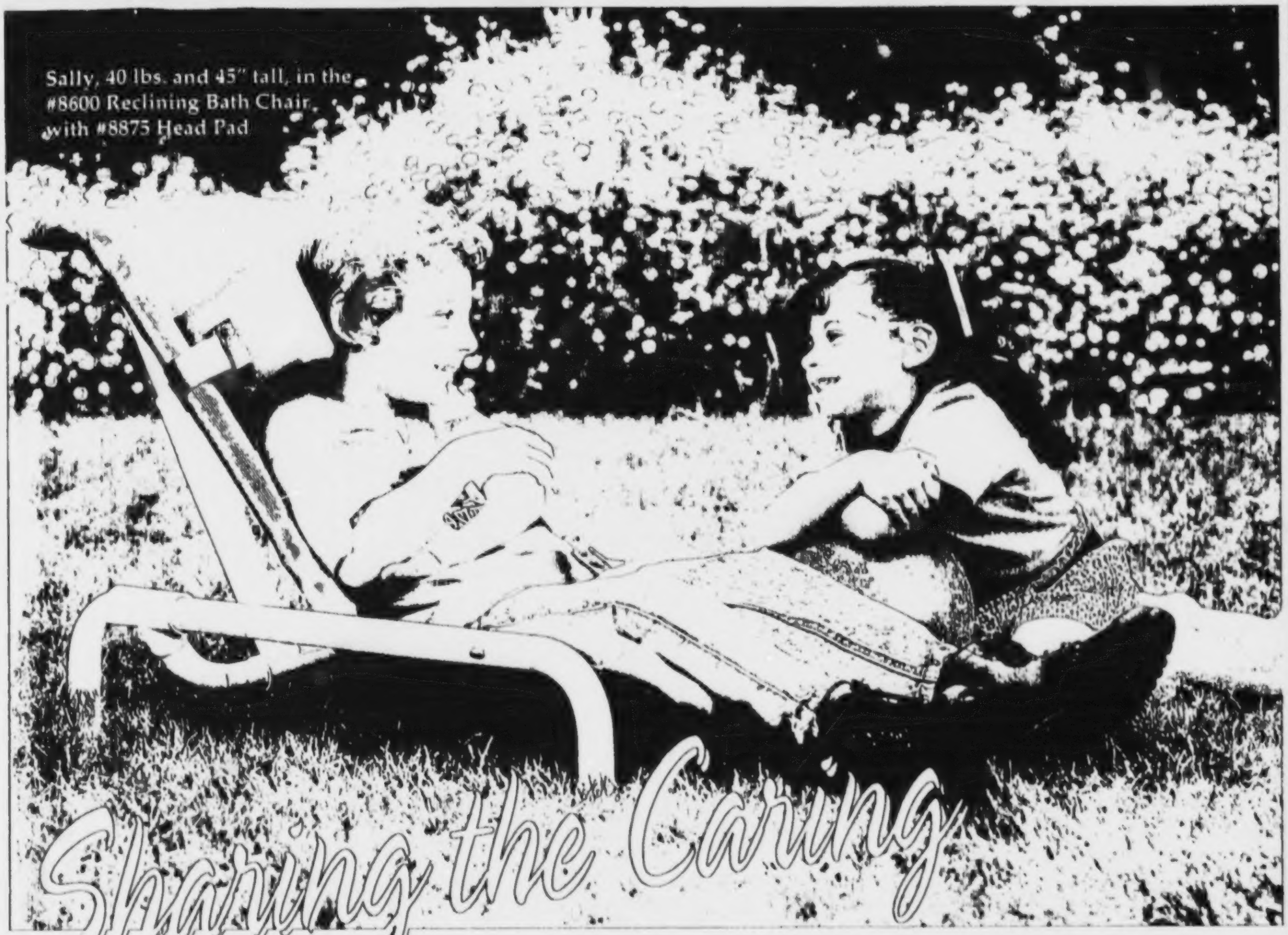
SUBSCRIBER SERVICE:
EXCEPTIONAL PARENT
P.O. Box 2078, Marion, OH 43306-2178.

CUSTOMER SERVICE/NEW ORDERS:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

EXCEPTIONAL PARENT magazine was founded in 1971 by
Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 66


Sally, 40 lbs. and 45" tall, in the #8600 Reclining Bath Chair with #8875 Head Pad

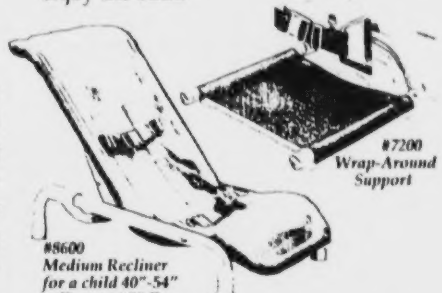
Columbia offers you solutions to the daily challenges of bathing, toileting and transporting your child – *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

☐ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.

#5800 Hi-Back Positioning Commode for junior adults

☐ At bathtime, our popular **Wrap-Around Bath Supports** and **Reclining Chairs** allow your child - and you - to enjoy the bath.


#7200 Wrap-Around Support

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

☐ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.-yet weighs only 11 pounds! Comfort, style and adjustability have made it the No. 1 choice since 1986.

#2000 Car Seat

Why do these products work so well?
Much thought and care go into the design of each Columbia product. We make each item in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, proven in real life. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

COLUMBIA
SHARING THE CARING

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG
Columbia Medical Mfg. Corp., Dept D2, P.O. Box 633, Pacific Palisades, CA 90272
Visit our web site at http://www.ColumbiaMedical.com

Circle #22 or visit www.eparent.com/adinfo

editor's desk

On Noticing A Noticeable Difference

ILLUSTRATION BY MS MEMORY COLLINS

It's not an unusual scenario. Concerned parents bring their infant to the pediatrician to report something they are observing or not observing. The physician calms the parents by saying "it's not so unusual," or "let's look at it in another six months." Most of the time the developmental milestone is reached, albeit on a timetable that isn't always by the book. Sometimes the parents will do their own rationalizing and turf the decision to mention it to the doctor, or not even see the doctor for another six months.

When growth deficits, developmental delays, sensory deficits or serious behavioral problems manifest themselves, they occur on a continuum. A child doesn't suddenly get diagnosed with failure to thrive or fine motor impairment or autism. When is something that's noticed noteworthy?

By age 2 years, the typical child runs well.

When do we see the red flags? When do we call for an assessment, when do we initiate treatment, when do we bring in the labels? When does "runs" become "runs well?"

The answer, of course, is based on perception, judgment, experience, school of thought and—certainly—comfort level. The latter reflects that of the clinician, the parent, the payors and the community. "Aggressive" pediatricians will perceive (and act on) things differently from conservative pediatricians. The actions of either will, of course, be modulated by the insistence of the parents, their practice environment and their instincts.

The preschool child normally grows about 3 to 5 pounds and 2.5 to 3 inches per year.

How does a thermos bottle know whether it's full of hot or cold liquid? How does a clinician know when to mobilize the troops of inquiry?

Most of the pediatricians I know will usually be at a loss to answer that question. You'll hear things like: "You just know;" "You'll know when you know;" "It somehow announces itself"; or "It will hit you." Not exactly pearls of wisdom the medical student can transfer from case to case, nor a response that would be applauded by an attending physician on rounds. So how does a clinician know and, more important, how does a parent know when to be alerted to these things? When does a mental note become an office visit?

By 7 to 9 months an infant will use partial thumb opposition to grasp pellets (and where do parents get these pellets, anyhow?).

How do we take what we observe as parents and professionals and assign them to the front or back burner of concern? When does "Oh" become "Oh!" or "Oh my!" or the defining "Oh my God!"? How do parents monitor coordination, when grasping and reaching (gradually) come under visual guidance and voluntary control? How do our perceptions of these things kick into gear? What's the impact of our fears, dreams, nightmares –and how do they temper, delay, or magnify our recognition of our kids' "red herrings"?

There's a science to these things, complete with laws, fractions, ratios and derived statistical measurements. Daily, parents and clinicians (and teachers, therapists and grandparents) unknowingly apply Weber's Ratio, Fechner's Law and Steven's Magnitude Estimation and decide whether what they see is worth one, two or three eyebrow raises. The "difference threshold" (or difference limen) is the smallest difference between two stimuli necessary to detect them as different. The difference threshold tries to answer questions: "is that response autistic or just indifference, that dropped coin clumsiness or pincer impairment?"

Only science could come up with the JND unit, the Just Noticeable Difference. How far do we have to increase the intensity of a tone before we can tell there's a difference? The magnitude of this difference in intensity specifies the difference threshold. How can parents become comfortable with "let's wait and see?" How do parents and professionals use the JNDs to form impressions, initiate action and redefine the notion of allowable and acceptable?

When does something become some THING?
When does a drizzle become rain?
When do words become prose?
When does an oral feeder become tube-fed?
When does consistent become constant?
And when does sensation become perception?
And when does "watchful wait" become "doing nothing"?

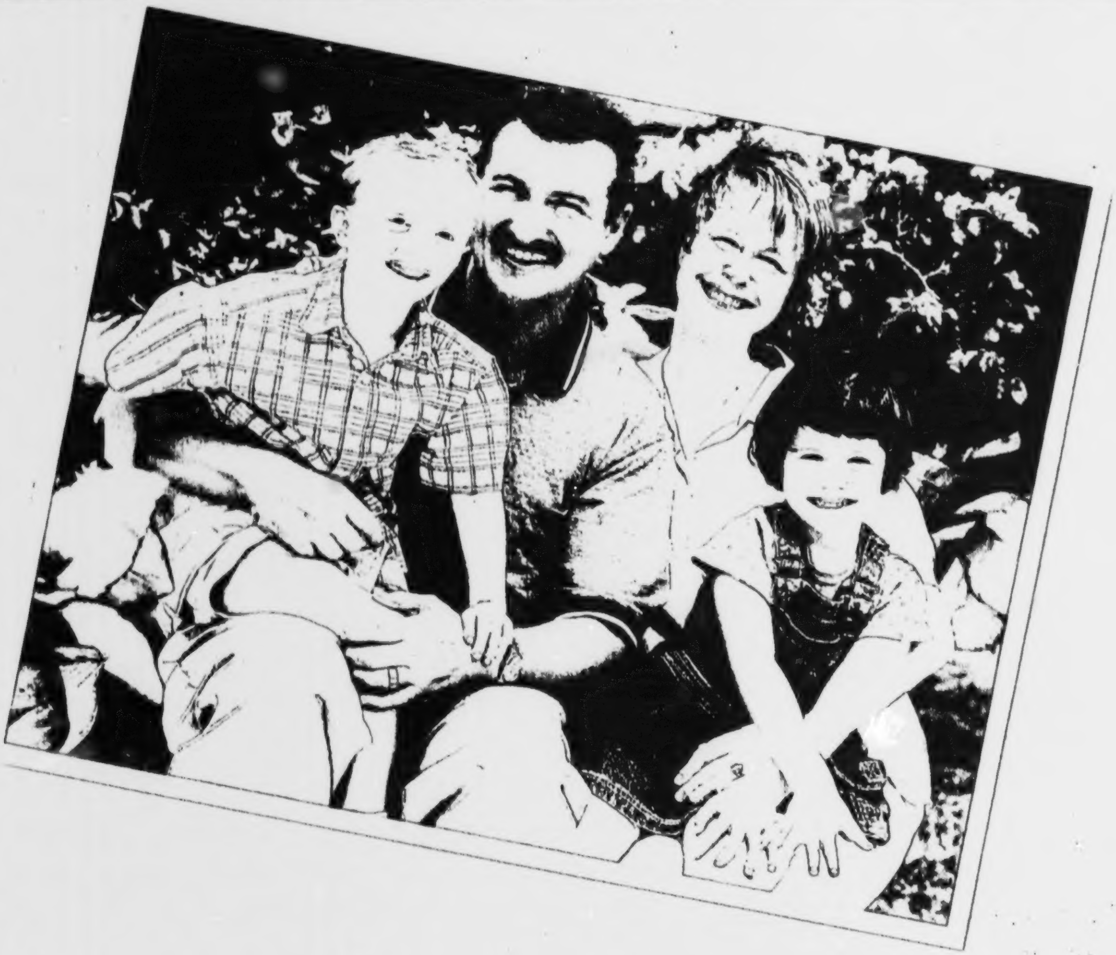
Beyond the framework of psychophysics, which examines the relationships between physical stimulation and subjective experience, lies your gut; and whether the gut is the gut of a surgeon, a soldier, a salesman or an exceptional parent, it's something you can often rely on. Sometimes it's the only bullet on the belt. Often you know it before the anthrometrics hit the boundaries of the borders. Call it a gut feeling, intuition, a voice from within or hoofbeats, it's there. And it's something that both parents and clinicians need to recognize, respect, consider and explore.

Early intervention begins with early assessment and early determination; and these assuredly begin with an early feeling, usually perceived somewhere in the center of a lawless land we call the gut. EP

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

Clay, Danny, Robin and Danielle Wagner live in Fort Lauderdale, Florida. Clay is autistic and has a seizure disorder.



"We're a PediaSure® Family."

"PediaSure helps us give Clay the nutrition he needs."

All kids need proper nutrition for growth and development. If your child is not getting enough of the right nutrition from regular food or has special feeding needs, ask your doctor about the complete, balanced nutrition of PediaSure. It's specially formulated to provide children with proper amounts of protein, fat, carbohydrate, vitamins and minerals. Available in your local supermarket, drug or discount store.

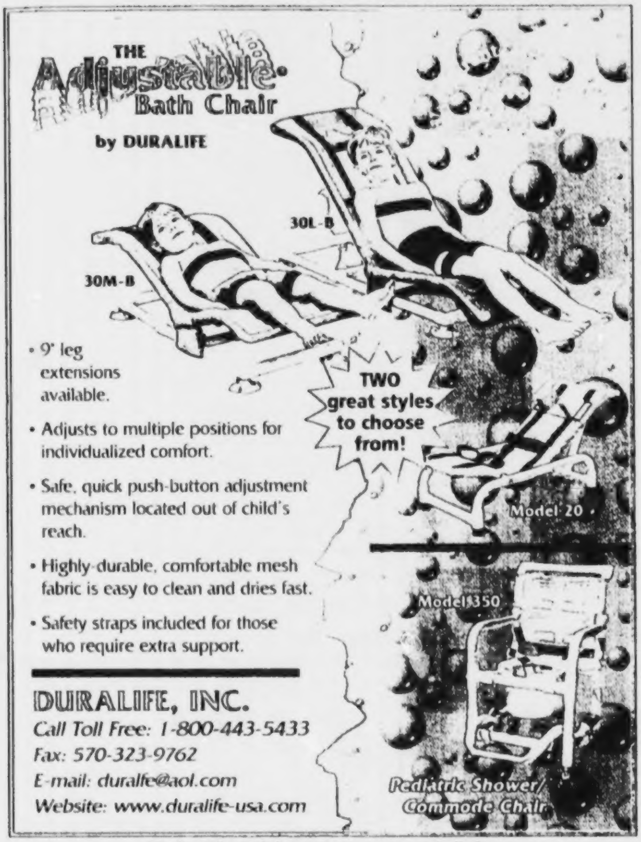
PediaSure
Pediatrician Recommended
Vanilla
Lactose Free

Available through WIC®*

*If your child has special dietary needs, check with your physician or local WIC clinic to see if your child is eligible to receive PediaSure through the WIC program. WIC is a registered trademark of the U.S. Dept. of Agriculture.

© 2001 Abbott Laboratories

Circle #46 or visit www.eparent.com/adinfo


THE Adjustable® Bath Chair
by DURALIFE

30L-B
30M-B
TWO great styles to choose from!
Model 20
Model 350
Pediatric Shower/ Commode Chair

- 9" leg extensions available.
- Adjusts to multiple positions for individualized comfort.
- Safe, quick push-button adjustment mechanism located out of child's reach.
- Highly-durable, comfortable mesh fabric is easy to clean and dries fast.
- Safety straps included for those who require extra support.

DURALIFE, INC.
Call Toll Free: 1-800-443-5433
Fax: 570-323-9762
E-mail: duralfe@aol.com
Website: www.duralife-usa.com

Circle #25 or visit www.eparent.com/adinfo

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #51 or visit www.eparent.com/adinfo

LESSONS TAUGHT BY THE CLASS OF 2001

To the Editor:
My name is Troy Daniels and I am a junior at Northfield High School. I have Down Syndrome. Because I have a weak heart, I sometimes use a wheelchair. I do not speak very well.

I want to tell you that inclusion is not a place, but a feeling. It wasn't too long ago that a person with a disability could not go to public school to receive an education. Labeled "retards," they were shut away in institutions without any link to the outside world.

Now that times have changed, there is a law that says all kids like me can go to school in their hometown. So I started school in my hometown of Northfield, Vermont as a member of the class of 2001. But even though I was allowed to go to school here, the law could not make people believe that I belonged there. The law did not change the prejudice that many people still felt towards me.

But along the way the kids in my class started to care about me. First, it was only one or two. Then others found out that they could be my friend. We were learning together. They wanted me to be here and they were willing to share with me. They called me a friend and made sure that I was included. I care about them and they care about me.

So I wanted you to see that my friends are not only students; they are the teachers of life. They show us how we should be. We are better inside when we can share with each other.

Thanks,
Troy Daniels

DISAPPOINTED IN THE GOV

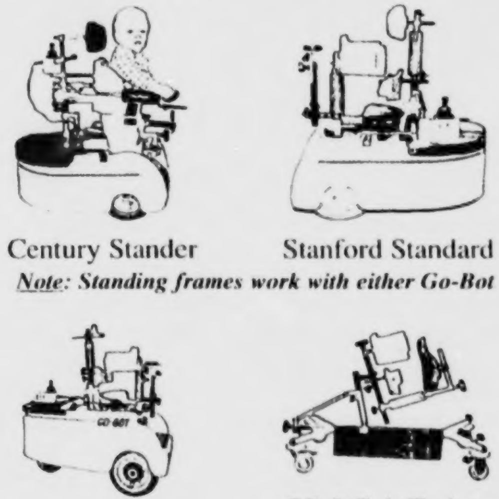
To the Editor:
I found it very interesting that Gov. Bush was on the cover of the December 2001 issue of EP. He has just decided to include the Choice and Control Pilot Project for consumers of the Developmental Disabilities Program in the budget cut list. He chose not to line item veto it (to save it) and maintain it for the remaining six months of the Pilot Project. What that means is that consumers like my son have lost the opportunity to have self-determination and control over the funds that he is eligible for. He, like the other consumers in this Pilot Project, will go back on the Medicaid Waiver. For now the opportunity to have consumer-directed services is lost. Although there are those in the state of Florida who continue to work toward this goal, the leadership has only offered empty rhetoric. I thought your readers would be interested in another side to the story.

Thanks,
Susan Redmon

EDITOR'S NOTE: In mid October, when Governor Bush was interviewed, he indicated that budget cuts were necessary, but did not specify which programs were subject.

continued on page 14

We encourage letters on any subject. Send them to: EP Magazine, Attn: Letter to the Editor, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com. Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified by full name and state. Please include your phone number and/or e-mail address on all correspondence in case we need to contact you directly.



Early Childhood Mobility
Mini Go-Bot's

Century Stander
Stanford Standard
Note: Standing frames work with either Go-Bot

Yellow Go-Bot
GB-I Gait Trainer
(can be customized)

Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com

Circle #35 or visit www.eparent.com/adinfo

SAVE Up To 50%
On Youth Briefs

We sell and distribute incontinent youth products at
DISCOUNT PRICES!
As a service to our customers, we offer
FREE SAMPLES
of disposable youth briefs and pull ups.

Save up to 50%
Call 1 800 777 1111 24Hrs
WOODBURY PRODUCTS, INC.
Order online at: www.woodburyproducts.com

Circle #58 or visit www.eparent.com/adinfo

continued from page 13

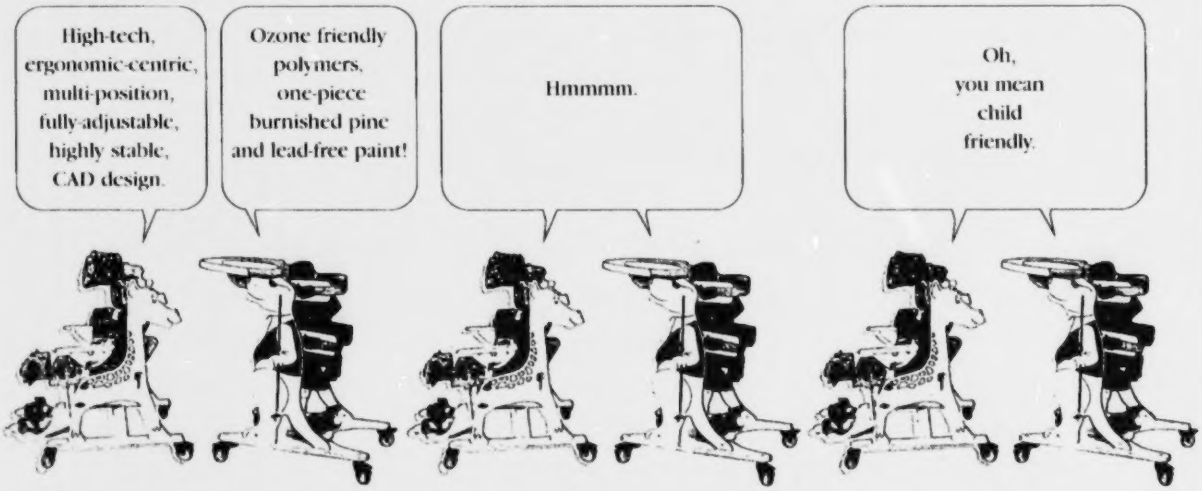
IMPRESSED WITH EXCEPTIONAL PARENT

EXCEPTIONAL PARENT
Health

Dear Dr. Rader:
I'm writing in regards to your magazine. I find the articles interesting, especially the article on Heather Whitestone (August 1995). I've also read the parents' stories of their trials and tribulations in rearing and nurturing their child/adult with disabilities. They also have to face the obstacles in finding the funds to help provide the accomodations needed to take care of their child/adult with disabilities. They also work tirelessly and endlessly to cope, in trying to find the best environment and the insurance that will help them to provide for their loved one. I also want to encourage the parents not to give up hope and to continue to strive as advocates for their rights and the rights of their child/adult with disabilities to be able to contribute to society.

I also find that the articles featuring persons who have hearing-impairments/ deafness really makes a difference for me, because I have a moderate to severe hearing loss in both ears. I also use sign language as a second method of communication. Learning to cope with it hasn't always been easy. I've chosen to make the sacrifices needed daily to help me overcome this disability. I also appreciate the different books and resource guides that are available to order at the end of this magazine. The teaching and sharing of stories about this issue are also helpful. Thank you, Mr. Rader for this opportunity to write to Exceptional Parent Magazine, to share my views. Best of wishes to you and the staff that have made this magazine possible.

Tomora M. Pace
ACDD


High-tech, ergonomic-centric, multi-position, fully-adjustable, highly stable, CAD design.
Ozone friendly polymers, one-piece burnished pine and lead-free paint!
Hmmmm.
Oh, you mean child friendly.

Introducing a brand new species of children's positioning equipment.

JENX
The perfect positioning. For body. And soul.

Distributed by BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #21 or visit www.eparent.com/adinfo

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C.
& Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #37 or visit www.eparent.com/adinfo

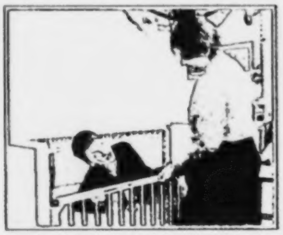
HARD MANUFACTURING

AGE APPROPRIATE

BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas



The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents. . . I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #32 or visit www.eparent.com/adinfo

EP has the information an "Exceptional Parent" like you needs

EP Exceptional Parent

Your paid subscription includes the EXCEPTIONAL PARENT 2003 Annual Resource Guide, which normally sells nationally for $19.95.

This invaluable reference tool is a "must-have" for exceptional parents

Save $5.00 by ordering on-line at: www.eparent.com

For telephone orders call: 877-372-7368

Circle #199

Subscribe and be part of a network of "Exceptional Parents"

EP Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web:

www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ______ Exp. Date ______

Name ______

Address ______

City ______ State ______ Zip ______

E-mail ______ Yes, I want more information to help me everyday.

Signature ______ E-mail ______

BFEB2

Subscribe and be part of a network of "Exceptional Parents"

EP Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web:

www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ______ Exp. Date ______

Name ______

Address ______

City ______ State ______ Zip ______

E-mail ______ Yes, I want more information to help me everyday.

Signature ______ E-mail ______

BFEB2

Make someone a part of a network of "Exceptional Parents"

EP Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95

☐ 2 Years (24 issues) $65.95

☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year.

Other foreign countries $57.95 per year.

PLEASE SEND MY GIFT OF EP TO:

Name ______

Address ______

City ______

State ______ Zip ______

THIS GIFT IS FROM:

Name ______

Address ______

City ______

State ______ Zip ______

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ______

Exp. Date ______

Signature ______

Save more money: Order off the Web: www.eparent.com

XFEB2

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer life for themselves and for their children.

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

Exceptional Parent's MISSION IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

EP
Exceptional
Parent

www.eparent.com

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our Web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Krause-Kivlin syndrome

My 6-year-old daughter was diagnosed with Krause-Kivlin syndrome when she was 6 months old. Her symptoms include seizures, kidney disorder (double collecting system with frequent urinary tract infections), small ventral septal defects (VSDs) of the heart, failure to thrive, glaucoma, short optic nerves, cloudy corneas and Peter's anomaly of the eye. There are very few cases in the world with this syndrome. Any information would be helpful.

-GS via the EP Web site

S

GT difficulty

I am raising my seven-year-old grandchild who has a profound brain injury and who had a fundoplication for gastroesophogeal reflux disease (GERD). As a result of the surgery, he experiences abdominal pain and distension that requires manual venting of his gastrostomy tube (GT) throughout the day. The tube bleeds at the site of insertion and internally with minimal manipulation. He is no longer able to lie on his abdomen and this impedes his progress in PT, OT, vision therapy, etc. The discs catch on his clothes, high chair and other people's clothes. It dangles between his legs, becomes caught and is pulled out when he attempts to sit up. Cognitively, he is unable to prevent this problem. Tape is not a possibility. I have tried a binder foam disc on top of the disc of the GT. Because of his need for continuous venting, he is not a candidate for a button GT. Any suggestions?

-SH via the EP Web site

S

School bus cannot enter gated community

Our son has cerebral palsy and attends public school. He has an Individualized Education Program (IEP) and doctor's documentation requiring an exceptional education school bus with climate control. We recently moved to a neighborhood with an electronic gate and the school system will not allow the bus to come into the neighborhood unless the access panel is modified. We have offered the bus driver a remote control (like a garage door opener) but the supervisor will not allow it. Does anyone have any experience with a similar circumstance? Would this situation be covered as a reasonable modification by the Americans with Disabilities Act (ADA)?

-KM via the EP Web site

Respond

R

Bathtub advice

VL (Oct 2001) has a 4-year-old son who has severe multiple disabilities due to complications from cystic fibrosis. VL's child has grown too large for an infant bathtub, and his equipment is too large for the bathroom. VL wants to hear from any parents who have dealt with a similar situation and who may have creative solutions.

As foster parents we have cared for a number of children that were difficult to bathe in a regular bath tub. Our solution was to use a deep laundry tub. They measure about 22 in. long x 17 in. wide x 13 in. deep and are made of reinforced fiber glass. They can be purchased at home improvement centers and/or plumbing supply stores.

-HM via the the EP Web site

I have dealt with a similar issue; I used a small inflatable children's wading pool in my living room. I propped my child's head up on an inflatable toy bat. Scooping water with dish pans, I was able to shampoo and bathe him this way. We would then transfer him to the side on a beach towel. This worked great.

-NL via the EP Web site

R

Feeling Isolated

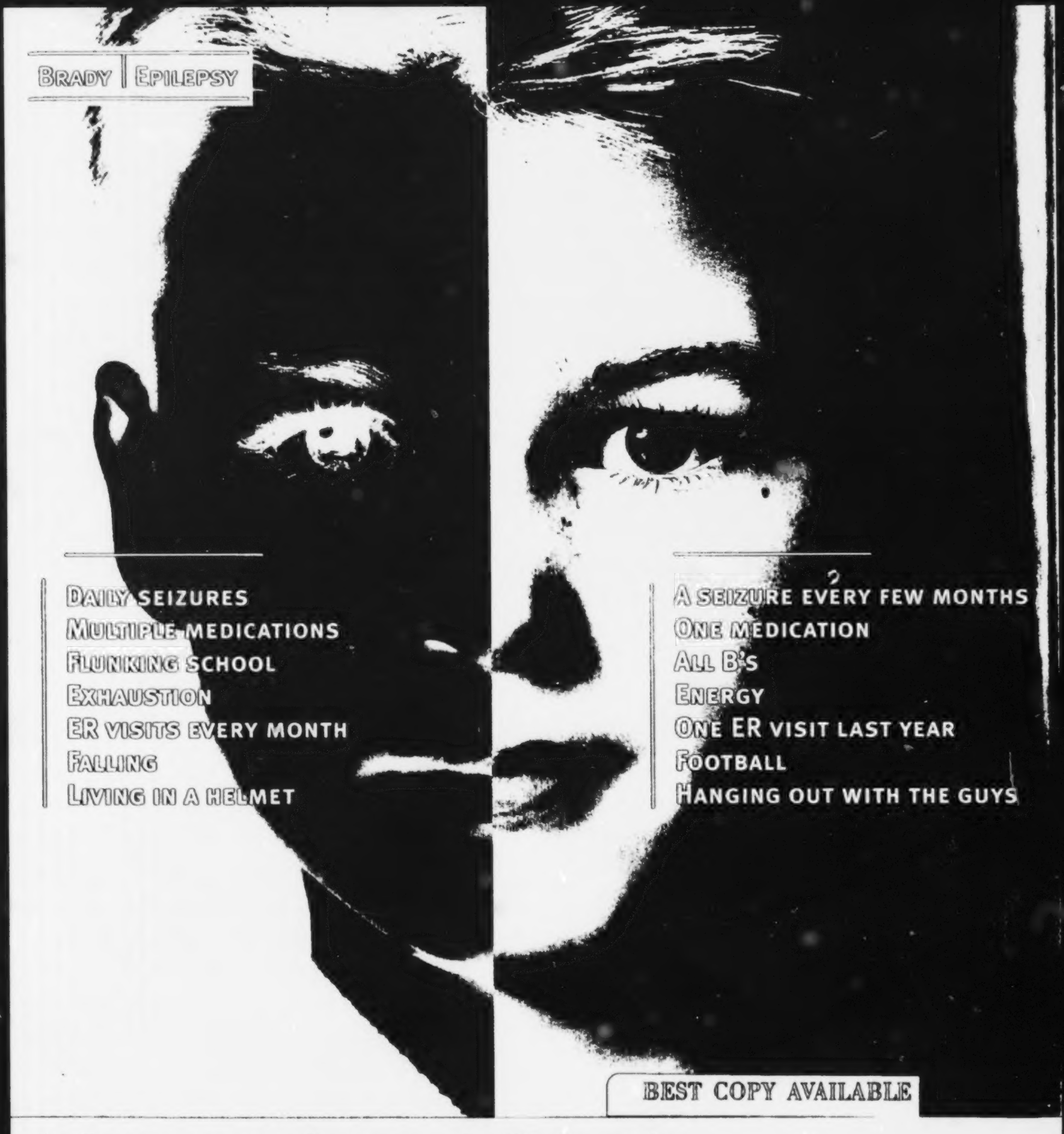
TK has a 4-year-old daughter with Angelman syndrome (AS). Her symptoms include microcephaly, uncontrollable laughter, seizures, absent speech, feeding difficulties and sleep problems. TK believes that the child is not receiving proper medical care and feels lost, alone and isolated.

I have a 27-year-old daughter with AS. She was not diagnosed until she was 25. Your little girl will grow up to be a wonderful person. When she becomes an adult, she will mellow and calm down. Our Patricia is a delight now, but it was very difficult until she was about 20 years old.

-CS via the EP Web site

We have a 4-year-old son who has AS with similar symptoms. You might want to visit the Angelman Syndrome Foundation's Web site,

continued on page 22


BRADY | EPILEPSY
DAILY SEIZURES
MULTIPLE MEDICATIONS
FLUNKING SCHOOL
EXHAUSTION
ER VISITS EVERY MONTH
FALLING
LIVING IN A HELMET
A SEIZURE EVERY FEW MONTHS
ONE MEDICATION
ALL B'S
ENERGY
ONE ER VISIT LAST YEAR
FOOTBALL
HANGING OUT WITH THE GUYS

BEST COPY AVAILABLE

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

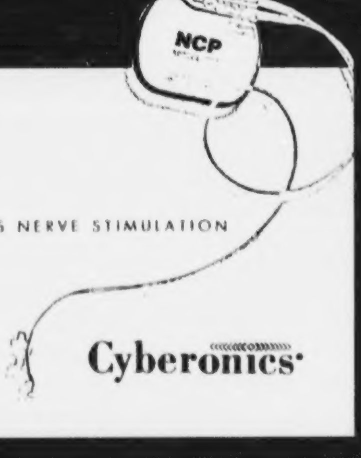
BEST COPY AVAILABLE

VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS THERAPY

VAGUS NERVE STIMULATION



Cyberonics

Circle #24 or visit www.eparent.com/adinfo

Search & Respond

continued from page 19

which has many links for medical professionals as well as information for families. For instance, most states have a Local Parent Contact for families who are coping with this disease. There is also an annual picnic. Meeting other Angelman families helps to build new friendships, establish support and benefit our angel kids. We have met many families in the past 3 years at picnics and other gatherings. To contact the foundation, call: (800) IF-ANGEL or visit their Web site at: http://www.angelman.org

–DT via the EP Web site

In addition to the Angelman Syndrome Foundation Web site, which includes a directory that lists parents of children who have AS, there are many other support groups for parents of children who have special needs. Our public school preschool program is a wonderful resource, and our speech therapist has worked with several AS children before. She currently has 2 AS, non-verbal girls in her care now, and I love hearing about their progress. Periodic crying jags and depression are definitely normal. Our daughter has a severe sleeping disorder, which is also typical of an AS diagnosis.

–BK via the EP Web site

Looking for Brushes

SR (Nov 2001) is looking for brushes with poly bristles, the kind used by surgeons for scrubbing up.

If you only need a few of these handy scrub brushes, you can buy them in the produce section next to the corn; they are used for brushing off the corn silk.

–BA via mail

Orthodonture for child with Down syndrome

Karla (Nov 2001) has an 11-year-old daughter with Down syndrome. The family dentist recommends that she have braces. Has anyone gone through this process? Is the outcome worth it emotionally and financially?

My 18-year-old daughter has cerebral palsy and cognitive impairment. Because she has had a lot of surgeries, she is absolutely terrified of any medical treatment. Three years ago, we decided to try to straighten her teeth, and we weren't optimistic. We were turned down flat by three orthodontists who weren't willing to work with her screaming, resisting, etc. We were then referred to a wonderful, patient orthodontist who had done a lot of work with children who have Down syndrome. This doctor always scheduled Sarah last so her noise wouldn't disturb other patients. She spent a lot of time talking to Sarah, showing her equipment and introducing her to the office staff, who treated her like a queen. I stayed out of sight, which also helped her work harder to control her fears. Amazingly, Sarah was fitted with braces and went through 2 years of treatment. Her teeth look wonderful, her drooling has decreased somewhat and her speech is easier to understand. Was it worth it? Absolutely!

–CM via the EP Web site

I work with a young lady who has Down syndrome who is 25 years old. Five years ago, she had braces placed both on her upper and lower teeth. Now that it's time to take them off, they found her teeth have shifted beautifully into place but have not "tightened" in again. Ultimately, if they remove the braces, her teeth will fall out. The orthodontist said this happened because her roots are short. Why they didn't know this before I don't know. I would at least ask about this before proceeding. Good luck!

–AH via the EP Web site

Hyperacute Hearing

DB (Nov 2001) has a 14-year-old daughter who has cerebral palsy, developmental delay and speech impairment. When she had her tonsils removed at age 11, she developed hyperacute hearing. The problem has progressed significantly, so that she shakes and trembles in anticipation of any noise. DB is looking for advice and information about hyperacute hearing.

My daughter is 8 years old and has hyperacute hearing along with several other disabilities. I have looked into a treatment called Auditory Integration Therapy (AIT). It is a way to retrain the ear to hear correctly. There is an organization that can explain how AIT works. It is called the Georgiana Institute, and it is based in Connecticut. The director/founder is Annable Stehli; her daughter Georgie suffered from hyperacute hearing and had been diagnosed with autism. She was cured of the problem by a doctor in France who founded AIT. I have spoken with Annable, and she is very helpful. For more information, visit their Web site: http://georgianainstitute.org

–BB via the EP Web site

My daughter is 11 years old and she had AIT therapy at the age of 10. Though it is not offered everywhere, you can search the Internet for locations near you. We went to Allentown, PA. The therapy lasts 30 minutes twice a day for a two-week period. It is non-invasive and all it requires the child to do is to listen through headphones to different music and sounds. My daughter has improved significantly; she can now go to restaurants, malls, doctor's offices, even bowling! Good luck.

–AC via the EP Web site

Instant S&R

Keeping the bed dry

My 11-year-old daughter is incontinent. She has multiple disabilities and mental retardation. During the day she is able to hold her urine if we take her to the bathroom regularly. At night, however, she frequently wets herself. I have her in pull-up diapers. I've bought plastic pants. I don't give her fluids after 7 p.m. Yet she keeps urinating through her diaper and plastic pants and I have to change the bedclothes daily. I need advice on how to keep the bed dry. We live alone, I work full time, and it is exhausting and expensive to do laundry daily. Any suggestions?

–SO via the EP Web site

Try an overnight diaper. I use Tranquility's All-Through-the-Night diaper with an extra booster pad inside. This prevents leaks for 12-14 hours. A supplier such as HDIS provides several brands and accepts many types of insurance.

–SM via the EP Web site

Try asking your doctor about DDAVP, a nasal spray which helps to reduce the amount of urine that the body produces. It worked for our family when we were dealing with bedwetting.

–CF via the EP Web site

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #57 or visit www.eparent.com/adinfo

Autism Fact Sheets Now Available From NICHD

The National Institute of Child Health and Human Development (NICHD) supports ongoing research to better understand autism, its causes and potential treatments. Now NICHD is making available a series of six fact sheets describing the latest research findings: Autism Facts; Autism Questions and Answers for Healthcare Professionals; Autism and Genes; Autism and the MMR Vaccine; Rett Syndrome; and The NICHD/NIDCD Network on the Neurobiology and Genetics of Autism: The Collaborative Programs of Excellence in Autism (CPEAs). These fact sheets are available for free. To contact the NICHD, call: (800) 370-2943 or visit the NICHD autism web site: http://www.nichd.nih.gob/autism/

Bears for the Kids

The Cleft Palate Foundation is the temporary home for hundreds of "cleft teddy bears" waiting to touch the lives of children and families affected by cleft lip and palate. The bears are custom-made by Gund, Inc. as part of the Foundation's "Bears for the Kids" project, which aims to help children cope with the questions and anxiety they experience from having facial differences. For more information about the project or to order a bear for your family, contact the Cleft Palate Foundation at: (800) 24-CLEFT, or visit their Web site: http://www.cleftline.org

New AAP Program Focuses on Universal Newborn Hearing Screening

The American Academy of Pediatrics (AAP) was recently awarded funds, in the form of a cooperative agreement with the Maternal and Child Health Bureau and the Centers for Disease Control and Prevention, for a program entitled, "Improving the Effectiveness of Newborn Hearing Screening: Diagnosis and Intervention through the Medical Home."

In a joint effort with the National Center for Hearing Assessment and Management (NCHAM), Utah State University and the Joint Committee on Infant Hearing, the AAP plans to disseminate educational materials, advocate state and local policy improvement, improve AAP state chapter Early Hearing Detection and Intervention (EHDI) programs and help identify problems in quality of programs.

SDSC Toll Free Number

The toll-free number of the Self Directed Support Corporation (SDSC) is now up and ready. SDSC is a group of not-for-profit corporations that are developed to provide a legal entity to manage the support system for a person with a disability. SDSC services help individuals to identify supports needed in life and to establish individual budgets, support brokerage and fiscal intermediaries. The goal of SDSC is the establishment of a person-centered corporation to meet the unique support needs of a person with a disability. The Inclusion Research Institute has established a toll free number to assist with questions regarding SDSC. To contact the institute, call: (888) 604-5752, ext. 250, or visit the Web site: http://www.inclusionresearch.org.

The National Arbor Day Foundation Announces Annual Poster Contest

The National Arbor Day Foundation (NADF) is inviting 5th grade classrooms across the country to showcase their artistic talent–while learning about trees– with its annual Arbor Day National Poster Contest. The theme is *Trees are Terrific...inside and out*. Students are encouraged to show off their creative flair by designing a poster to reflect this theme.

The winner of 2002 poster contest will be announced on Arbor Day (April 26, 2002). The first place winner, his or her parents and teacher will receive an expense-paid trip to Nebraska City, NE, where they will participate in the National Awards Weekend in addition to receiving a $1000 savings bond and a lifetime membership in the NADF. The winning student's teacher will receive $200 for classroom materials. Second and third place also receive savings bonds and funds for classroom supplies. To receive a free activity guide on how trees function, including in-depth lesson plans, educators can sign up by writing to: NADF, P.O. Box 85784, Lincoln, NE 68501-5784, or by sending an e-mail to: education@arborday.org.

Technology and Persons with Disabilities

The 17th annual conference *Technology and Persons with Disabilities*, sponsored by the Center on Disabilities, California State University, Northridge, will be held March 18-23, 2002 in Los Angeles. Gregg C. Vanderheiden, a pioneer in the field of augmentative communication and assistive technology, will be the featured keynote speaker. For additional information, contact: Conference Staff, Center on Disabilities, California State Univ. Northridge, 18111 Nordhoff St., Northridge, CA 91330-8340; Phone/TTY: (818) 677-2578; Fax: (818) 677-4929; E-mail: ctrdis@csun.edu; Web Site: http://www.csun.edu/cod

NOTATIONS

- Linda Thomas, author of *Living with Prader-Willi: The Starving Syndrome*, would like to acknowledge the assistance of Theresa Strong, PhD, chair of the Scientific Board of the Prader-Willi Alliance for Research, who "provided invaluable contributions to the technical content of the article." This feature can be found on page 66 of the November 2001 issue.

- In *Remembering Malki* (December 2001, page 62), we failed to include contact information for The Malki Foundation; this non-profit provides essential and practical assistance to families in Israel caring for children with severe disabilities so that their child can remain at home for care as long as possible. Web site: http://www.kerenmalki.org; Phone: (508) 462-8555; Mail: Attn: Frimet & Arnold Roth (AFKM), PO Box 23637, Jerusalem 91236 ISRAEL.

LAWYERS INCORPORATED, P.C.

AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

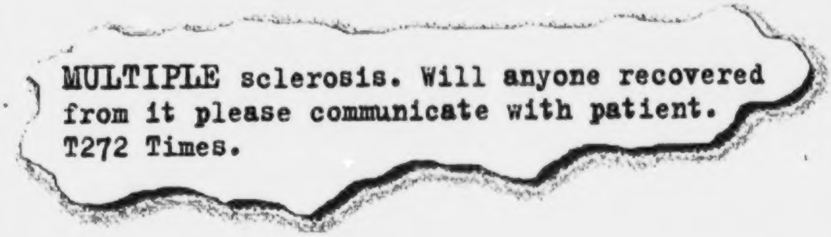
Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #38 or visit www.eparent.com/adinfo

book notes

Courage

by Richard Trubo
Ivan R. Dee, Publisher, Chicago
Pages: 320 • Price: $27.50
Review by Jerry Levinson



MULTIPLE sclerosis. Will anyone recovered from it please communicate with patient. T272 Times.

Courage, as defined by Webster's Dictionary, is "the attitude of facing and dealing with anything recognized as difficult, or painful, instead of withdrawing from it; also the courage of one's convictions to do what one thinks right."

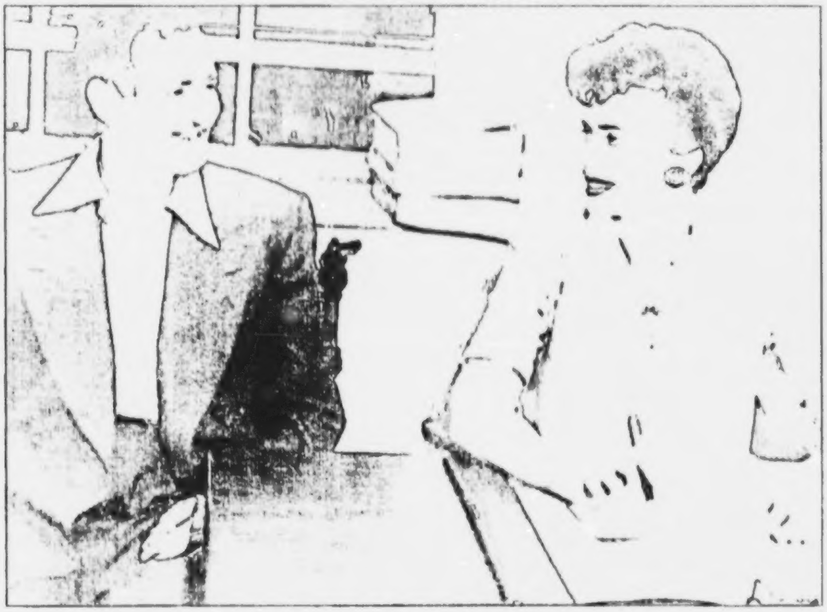
The definition perfectly describes the character of Sylvia Lawry, the woman who founded the institution that is today known as the National Multiple Sclerosis Society (NMSS). The word defined is also the title of the book chronicling her efforts.

In *Courage*, author Richard Trubo tells how Lawry, whose brother Bernard was diagnosed with MS in the 1930's, put her own dreams on hold, deciding that the defeat of the disease would be her life's work. As the Acknowledgements to the book recite, her commitment to defeating MS was her "magnificent obsession."

Once the initial shock of her brother's diagnosis subsided, Lowry began to investigate the cause or causes of MS, and whether there was a recommended treatment and cure for the disease. To her dismay, at the time little to nothing was known about the condition. Even more disheartening, many doctors would not see, let alone treat, people with MS, believing nothing could be done to help them. It was not uncommon for people with MS to be given a prognosis of five years to live, maximum.

For those with MS, the absence of information about the disease and the bleak outlook for the future were compounded by the almost total absence of research into the disease and lack of funds devoted to that purpose. There was nowhere for MS patients and their families to turn for answers, and little reason for optimism.

Courage describes how Sylvia Lawry refused to accept this black hole of information about MS, and tells how her novel and unconventional step of advertising in the *NY Times* for information about anyone who had "recovered" from the disease led to the realization that many individuals with MS wanted more information, research and hope. The book then depicts how she worked tirelessly to form the Association for the Advancement of Research on Multiple Sclerosis (the predecessor of the NMSS). She assembled the organization's medical advisory board and obtained funding for the organization's research and patient-assistance efforts by increasing public awareness of the disease—a not-inconsiderable achievement at a time when the majority of the public had never even heard the words "multiple sclerosis." As *Courage* recounts, Lawry's accomplishments are all the more astonishing because they "occurred in an era when women were not taken seriously enough."

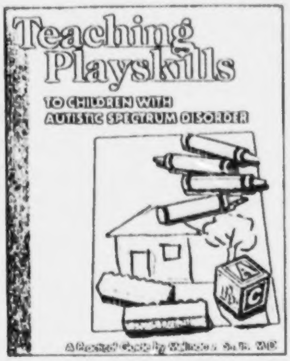


Sylvia Lawry with her brother, Bernard.

Sylvia Lawry died in March 2001. However, her determination, persistence and entrepreneurship created a living legacy of MS societies in every state of the union and throughout the world, organizations that are devoted to promoting research into the cause and treatment of the disease, assisting MS patients and their families, and eliminating the devastating effects of MS. *Courage* details Ms. Lawry's efforts to end MS and form the NMSS by describing each step in her personal efforts to ultimately conquer this baffling disease.

Sylvia Lawry

Jerry Levinson is an attorney and president of Benefits Research & Communications, Inc. of San Diego, CA. He is also editor of Aspen Publishers' Journal of Compensation and Benefits Management. He is a graduate of Boston College and lives with his wife Dorothy and three sons in San Diego. Jerry has had MS for 33 years.



Teaching Playskills to Children with Autism Spectrum Disorder

by Melinda J. Smith, M.D.
Published by DRL Books
New York, 2001
Available from the EP Library
(800) 535-1910
Code: DR6635AT
Cost: $24.95 plus shipping and handling.

Drawing on her experience as a mother of a child with autism spectrum disorder (ASD), author Melinda Smith, MD narrates *Teaching Playskills to Children with Autism Spectrum Disorder* from a concerned, observational standpoint motivated by her struggle to guide her son's playskill development. The project started in 1999 as a culmination of her research and personal experience; she created the Web site *Teaching Playskills to Children with Autism Spectrum Disorder*, http://melindasmith.home.mindspring.com. After confirming her child's diagnosis with extensive research, Smith embarked on a two-year journey of Applied Behavioral Analysis (ABA) therapy; her book reflects that process and includes notes by her son's tutors in almost every chapter. Also included are excerpts from other parents coping with ASD; these anecdotes are helpful and revealing, drawing contrast to the experiences of Smith's son. Because this is Smith's first experience with ABA, the reader benefits from her true-to-life narrative, experiencing common pitfalls and unexpected insights alongside her. She gives tips for planning, building and guiding your child's play, as well as suggestions loosely based on her own experiences. Smith wisely includes pros and cons for most techniques, approaches or exercises and is ever mindful that ASD can manifest in a variety of ways in different people.

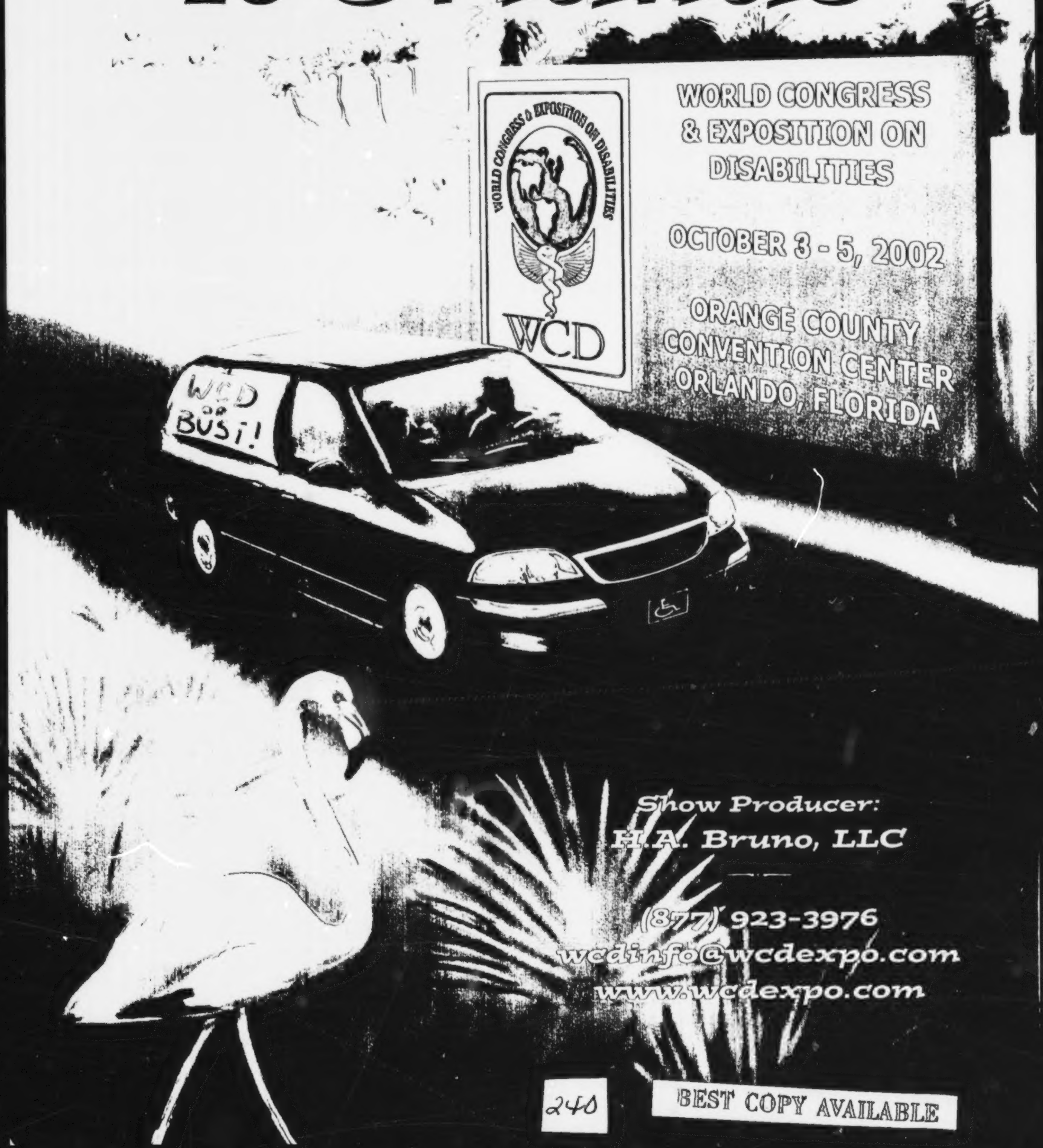
Informally organized, the book first addresses the issue of play, its role in a child's cognitive and social development, types of play and teaching playskills to a child with developmental delays. Smith describes the "mythical child" –which parents too often glorify– that picks up his toys and who doesn't make too much noise; the autistic child, Smith opines, is just "more," that's all.

The next ten chapters, the bulk of the book, describe, evaluate and exemplify differing modes of play. With personal narratives, tutors' notes and outside excerpts, Smith explores what works and what doesn't and why; how to deal with inappropriate behavior; the relative worth of a playskill unmastered versus a child's peace of mind; peer involvement and its value; and hundreds of ideas to initiate play with your child.

Play is organized into the following groups: imitative, manipulative, toy, in-vivo pretend, in-vitro pretend, game, musical, sensory/physical, water/sand, and creative. Drills, techniques, targets, materials, examples, types and rules are included.

Smith takes the last four chapters to address social forms of play. Drawing a distinction between playdates (one or two peers) and playgroups (several peers), Smith gives prerequisites, goals and warnings, addressing difficult peer issues such as dealing with other people's children and their rudeness and lack of response to your child; the stigma among children that is associated with pretend play, viewing it as "babyish"; and your child's lack of attention span. Smith gives advice on how to build a playdate "pool" that nurtures your child. For example, peers from therapy and their siblings, who are often "accustomed to special needs behavior," often make excellent playdates. Making connections like these can help to reincorporate your child's siblings into play, since, Smith notes, they can become estranged from the sibling relationship when ASD is present. The final chapters focus on the transition of play to older groups, where structured games can become powerful. Some fun recipes for slime and putty are included along with a bibliography and a listing of toy companies and their products.

On The Road To Orlando


WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD
WORLD CONGRESS & EXPOSITION ON DISABILITIES
OCTOBER 3 - 5, 2002
ORANGE COUNTY CONVENTION CENTER
ORLANDO, FLORIDA
WCD or BUST!

Show Producer:
H.A. Bruno, LLC

(877) 923-3976
wcdinfo@wcdexpo.com
www.wcdexpo.com

BEST COPY AVAILABLE

Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—October 3 - 5, 2002
LOCATION:
Orange County Convention Center—Orlando, Florida

A UNIQUE GATHERING—A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract

physicians • families ○ direct support professionals ○ people with disabilities ○ allied health care professionals • educators ○ adapted physical education specialists.

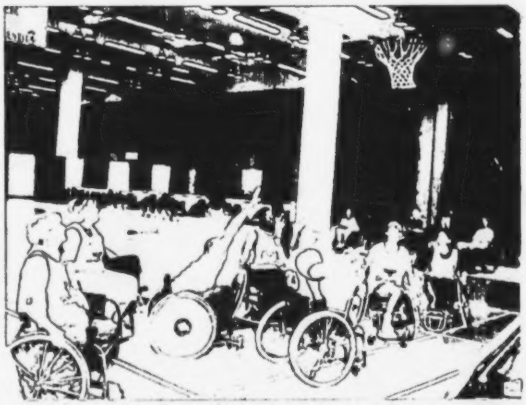
TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.

SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more.

EMPLOYMENT SYMPOSIUM PAVILION: Human resource managers will discuss career opportunities.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.



CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment.

- All WCD attendees can experience discussions by internationally renowned experts specializing in neurology, orthopedics, pediatrics, internal medicine, family medicine, physical medicine, epidemiology, DDS, movement disorders, mitochondrial and metabolic disorders, neonatology, seizure disorders, autism, and other disabilities and chronic conditions as well as general practitioners.
- CME and CEU accreditation will be provided through approved accreditation institutions.
- Hear parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.
- An Employment Symposium produced in conjunction with the Florida Department of Education, Division of Vocational Rehabilitation Services will offer sessions for people with disabilities, their families and employers.
- Learn from special education professionals what is going on in classroom environments.
- Participate in adapted physical education activities and seminars.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

FOUNDING SPONSORS: ALLERGAN | sigma-tau PHARMACEUTICALS, INC. | EP Exceptional Parent

CONFERENCE SPONSOR: EP Foundation for Education, Inc.

October 3-5, 2002 ○ WORLD CONGRESS & EXPOSITION ON DISABILITIES

Third Annual WORLD CONGRESS & EXPOSITION ON DISABILITIES Gears Up For Exciting Move To Orlando

The Second Annual World Congress & Exposition on Disabilities (WCD) that took place September 28-30, 2001 in Atlanta was a major success. The event drew more than 5,000 people from across the country and received high praise from attendees and exhibiting companies.

"The World Congress & Exposition on Disabilities was one of the most rewarding events I have ever attended. It really was a two way street between us and our patients because I learned as much or more from them as they did from me. The WCD was both an educational and motivational experience for me," said John Knudsen, Shire US Inc.

Produced by H.A. Bruno, LLC, the WCD is a comprehensive forum that educates, informs, and provides a useful exchange of ideas for persons with disabilities and special health care needs, as well as those involved in their care and development. Attendees at the WCD include physicians, physical therapists, occupational therapists, social workers, speech and language pathologists, nurses, special education and adapted physical education teachers, direct service providers, people with disabilities and their families and caregivers.

In 2002, the WCD will take place at the Orange County Convention Center in Orlando, Florida on October 3-5. "We're very much looking forward to moving the event to Orlando," stated Steve Gross, Director of the WCD. "The reception we have received from many local and state disability groups, as well as some state government organizations has been incredible."

Florida Governor Jeb Bush will be the Guest Speaker at the WCD this year. The impressive list of invited keynote presenters include Bob Pasternak, the new Assistant Secretary of the US Department of Education from the Office of Special Education and Rehabilitation Services; Dr. Robert Steadward, past President of the International Paralympic Committee; and Dr. Francis Collins, Director of the National Human Genome Research Institute.

The WCD will continue its incredible conference by offering over 150 sessions. The uniqueness of this program is the multi-disciplinary focus. Each seminar is designed to educate many disciplines within the disability community. The conference program is sponsored by the EP Foundation for Education, Inc., a 501(C)3 not-for-profit organization, with the assistance of EP ("Exceptional Parent") magazine. From pediatrics to geriatrics, some of most important issues and topics in the disability arena will include: autism, ADD/ADHD, dystonia, epilepsy, estate planning, genetic disorders, IDEA, learning disabilities, movement disorders, newborn screening, perinatal care, spasticity and The Medical Home. An adapted physical activity program will offer sessions on sensory and gross motor activities, biomechanics for inclusion in PE as well as extracurricular and after-school activities. A special focus on assistive technology will be added to the educational program with topics and presenters from CSUN. In addition, collaboration on a 50 session employment symposium with the Florida Department of Education, Division of Vocational Rehabilitation Services (VRS) and other statewide provider/advocacy organizations rounds out the conference.

The exhibit floor will once again host a wide array of the latest, products and services from more than 250 exhibitors

Virtual WCD
www.vwcdexpo.com

☐ View the latest products and services
☐ Read updated news items
☐ Communicate with people in the disability community
☐ Use the comprehensive bulletin board

representing many industries. The majority of exhibitors from last year are returning, some of which include Sigma-Tau Pharmaceuticals, Advanced Respiratory, Ford Motor Company, McDonald's Corporation, Guldmann, Shire US, Pride Mobility, The Liberty Motor Company, Allergan Pharmaceuticals, Pathways Design, Theradapt, Flaghouse and Magitek as well as many others in the pharmaceutical, assistive technology, automotive, mobility, durable medical equipment, personal care, insurance, computer, nutrition and many other industries. Some of the exhibitors include Convaid, Sunrise Medical, Ricon and Bodypoint Designs offering their strollers, wheelchairs and other mobility products; Acorn Stairlifts; Economic Mobility and Anew with personal care products; Sammons Preston; Hewlett Packard; and many more. Along with its employment symposium, the VRS is working closely with the WCD in producing a major disability employment pavilion on the show floor.

And... back by popular demand... The Sports & Recreation Activity Center promises to be a major attendee attraction. Activities such as basketball, tennis, fencing, rugby and track and field will take place right on the show floor and professional demonstrations will be followed by audience participation.

Sponsoring organizations have always played a critical role in the WCD. Through their efforts, the significance of the WCD for the disability community is disseminated. Over 30 national and regional organizations are sponsoring the event, most of which will also be at the show to discuss their goals and how they can best support those in need. Some of those participating are the National Institutes of Health, Muscular Dystrophy Family Foundation, Special Olympics, American Academy of Pediatrics, National Multiple Sclerosis Society, TASH, American Association on Mental Retardation, WE MOVE, Council for Exceptional Children, UCP, Family Voices, Spina Bifida Association of America, National Parent Network on Disabilities, Child Neurology Society, American Association for Active Lifestyles & Fitness, National Perinatal Association, and AAUAP.

Sponsoring publications are also important to this national event. EP ("Exceptional Parent"), PALAESTRA, New Mobility, Today's Caregiver, Disabled Dealer of the Southeast, Active Living Magazine and Teaching Exceptional Children are just some of the magazines currently supporting the WCD.

CAN
COMPANIO
EPENDE

> ***"That event (the World Congress & Exposition on Disabilities) was magnificent. You have a subgroup, a session, for every subject under the sun. It's the most comprehensive educational program I've ever seen in any one setting."***
>
> **—Governor Jeb Bush**

Please send me information on the World Congress & Exposition on Disabilities, October 3-5, 2002

I AM INTERESTED IN: ☐ Exhibiting at the Show ☐ Attending the Show

Name

Company

Address

City State Zip Code

Telephone Fax

Email

Send Me Information:
877-923-3976, x832
Fax this page to:
201-226-1236
Mail this page back to:
WCD
210 Route 4 East
Suite 403
Paramus, NJ 07652
Email your request from:
www.wcdexpo.com

For complete details, visit our website at www.wcdexpo.com, or call: (877) 923-3976 • (201) 226-1446

Effective Social Skills Programming

The May Institute, Inc.

This article has been developed for parents of children with difficulties in social interactions. In particular, parents of children with special needs—mental retardation, pervasive developmental disorders (PDD) and other disorders where social behavior is of concern—may benefit from the information presented here on promotion of social skills in young people.

Good social skills are important tools for day-to-day living; they help children navigate social interactions effectively and smoothly. The most basic and essential skill is the ability to communicate with others. Social skills are the specific behavioral strategies that allow one to initiate and maintain positive social interactions with others, develop friendships and social support networks, and cope effectively with the social environment.

> As with academic subject matter, social skills can be taught, both at home and in school.

Children have many important social relationships to negotiate:

With parents and direct support professionals (DSPs): they must be able to follow directions, sit quietly when needed, assist with household chores and self-care as possible, and communicate needs in an appropriate way.

With teachers: they must be able to respond to teachers' behavioral expectations.

With peers: they must meet the behavioral requirements of peers in free play settings.

Importance of promoting social skills and prosocial development

Studies have demonstrated that a child's social competence is a critical developmental achievement for later social success. Social competence has been strongly associated with successful school performance, transition into school and work settings, better job opportunities and corresponding adult support, and improved overall interactions with others. Without intervention, children who demonstrate poor social skills may continue to experience problems into middle childhood and beyond.

Children with good social skills are better accepted by their peers, have better coping and attention skills and make better adjustments to school and social situations. Children with poor social skills have a greater risk of developing patterns of aggressive behavior and experience higher rates of emotional and behavioral problems. Developmental delays, however, affect the ways children demonstrate and develop social skills.

People with mental retardation show impairment in at least two adaptive skill areas such as communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work.

There are several ways in which people with PDD may be weak in social skills.

Qualitative impairment in social interactions: People with PDD may have impairment in the use of such nonverbal behaviors as eye gaze, posture, facial expression or gestures; or they may fail to develop peer relationships appropriate to their developmental level. They may not understand social and/or emotional reciprocity and generally do not spontaneously seek to share their interests and achievements.

Restricted, repetitive, and stereotyped behaviors, interests, and activities: There may be preoccupation—abnormal in intensity or focus—

with one or more restricted, stereotyped interests. People with PDD may demonstrate inflexible adherence to specific, nonfunctional routines or rituals, stereotyped or repetitive motor mannerisms, or persistent preoccupation with parts of objects.

Qualitative impairment in communication: This may be a delay in or total lack of the development of spoken language. If speech is adequate, there may be an impaired ability to initiate or sustain conversation. Stereotyped and repetitive use of language and idiosyncratic language are common, as is lack of varied, spontaneous pretend play or social imitative play.

Social Skill Deficits

With an acquisition deficit, the child does not know how to perform particular skills. For example, Jack stands by the wall while watching a circle of his friends; he wants to join in but doesn't know how to start the process. A child with a performance deficit has the skill but does not use it. So Jim can raise his hand in class, but instead he yells out to get his teacher's attention.

There are both formal and informal ways to help children with social skill deficits. Formal interventions for this purpose are usually called "social skills programming."

Developing Effective Social Skills Programming

Social skills programming is a psychological and educational intervention for students with social skill deficits; it is used to strengthen social interactions and improve self-control. As with academic subject matter, social skills can be taught,both at home and in school.

FOUR KEY AREAS

1.Social Skills Assessment

The first step in developing effective social skills programming is an assessment of your child's social skills, both strengths and deficits; it identifies areas to be worked on. As mandated by the Individuals with Disabilities Education Act (IDEA '97), school-aged children with developmental delays are required to have an Individualized Education Plan (IEP) that specifies the services necessary for a student's successful performance in a given setting. An assessment will thus provide guidance for this portion of the IEP.

> Your child's social competencies will be compared to those of "typical" students, allowing parent and others working with the child to understand better the child's progress in developing age-appropriate skills.

Measurement Strategies

Informal observations and feedback from a parent, DSP, and other people who know your child very well can offer helpful information about his current skill level in areas such as joining an activity and asking for help in appropriate ways. **Formal assessment strategies** help to provide objective information about how a child's current abilities compare with those of her peers. Tools have been designed to test cognitive and intellectual ability, adaptive functioning, personality measurements, functional behavioral assessments, and others.

Empirically-based assessments are developed through careful testing with the targeted population. Testing is often conducted with a large number of children of various ages, backgrounds, and abilities to determine whether the assessment measure or tool is reliable and valid for understanding children's patterns of behaviors. Reliability means that the assessment tool consistently provides the intended information in an accurate fashion. Validity means that the test really does measure what it is supposed to measure: intelligence, social competence, achievement, etc.

Advantages of Using Empirically-Based Assessment Measures

Your child has both strengths and weaknesses in of social skills. These assessments will measure them more precisely. Your child's social competencies will be compared to those of "typical" students, allowing parent and others working with the child to better understand the child's progress in developing age-appropriate skills. Children commonly show different behaviors and skills when in different settings with different care providers, so social competencies as evaluated by different observers can be compared. By using the same assessment tool to track progress, parents and teaching staff can determine if the social skills intervention is working or if there are areas needing additional intervention.

Functional Behavioral Assessment (FBA) is one type of formal evaluation. For those students with challenging behavior, a functional behavioral assessment may be necessary. FBA is a process for gathering information that can be used to maximize the effectiveness and efficiency of behavioral support because the problem behavior is evaluated in context. An FBA is a means for understanding the

continued on page 34

continued from page 33

antecedents and consequences associated with social skill deficits by providing information about when, where, and why problem behaviors occur. The underlying rationale of the process is the assumption that behavior is functional: individuals engage in patterns of behavior that work for them in some way; there is a logic to the target behavior, and functional assessment is an attempt to understand that logic. By looking at the relationship between behavior and a child's environment—schedules, activity patterns, curriculum, teachers, physical settings—we can identify clues about the factors that support the target behavior.

Several strategies are used to conduct an FBA, including interviews and direct observation. This type of assessment is especially helpful when there is no agreement about the processes that appear to maintain the behavior. An FBA is especially needed when severe problem behaviors are a concern; IDEA '97 now requires that an FBA be conducted for any child who is suspended from school for more than 10 days because of behavioral problems.

Answers to specific questions help to inform an FBA evaluation:

- ***What are the behaviors that are causing concern?***
- ***What events or physical conditions that occurred significantly earlier in time than the problem behavior increase the likelihood that the problem behavior will recur?***
- ***What events and situations that occur just prior to the problem behaviors reliably predict occurrence of problem behaviors?***
- ***What events reliably predict when problem behaviors will not occur?***
- ***In a specific situation when the problem behavior occurs, what are the consequences that appear to maintain the problem behavior?***
- ***What appropriate behaviors, if any, could produce the same consequences that appear to maintain the problem behavior?***

Priorities for immediate intervention

Behaviors that are physically dangerous; would enable the student to have better access to more inclusive activities; provide a positive approach; are precursors to later, more complex skills; or alter the perceptions of others and thus have long-term positive implications are priorities for intervention.

2. Curriculum Selection and Implementation

The second key in developing effective social skills programming is selecting a well-designed social skills program that will address your child's deficits. The results of the social skills assessment should help guide the decision-making and selection process.

What to look for in a social skills curriculum or program

Numerous social skills curricula are available on the market (see Resources). A validated social skills curriculum has been research-tested and found to be effective for improving social skills. Implementing a social skills curriculum will require time and effort on the part of many people who work with your child; select a program that you can be confident will bring about the needed

A Summary Checklist

Assessment

☐ 1. An assessment has been conducted to measure my child's social skills.
☐ 2. Standardized, empirically-based measures are used to assess my child's social skills.
☐ 3. Results provide information about my child's social skill deficits and strengths.
☐ 4. If my child exhibits challenging behaviors, Functional Behavioral Assessment is conducted by a qualified professional.

IEP Development

☐ 1. Goals and objectives target specific social skill deficits.
☐ 2. Goals target priority areas for intervention.
☐ 3. Goals and objectives are measurable.
☐ 4. Goals allow for change over the course of a year.
☐ 5. Goals and objectives include measurable benchmarks.
☐ 6. Data collection systems are in place to measure progress toward each of the goals and objectives.
☐ 7. Changes are made to social skills programming or goals as indicated by the data.

Social Skills Programming

☐ 1. Social skills programming is matched to the target areas for which my child needs intervention.
☐ 2. For direct skill instruction, key features are incorporated: modeling, coaching, role-playing, performance feedback, reinforcement, and

regeneralization procedures.

☐ 3. If a curriculum is used, it is one that has been validated.

☐ 4. Includes instruction for skills that are useful at home

Staff Qualifications

☐ 1. Consultant is qualified to develop appropriate social skills programming based on assessment results and needs of my child.

☐ 2. Staff are qualified to implement social skills programming.

☐ 3. Staff who implement social skills programming are knowledgeable in mental retardation and/or pervasive developmental disorders, functional behavioral assessment, social skills assessment, best instructional practices, applied behavior analysis, social skills training, and behavior support plans.

☐ 4. The behavioral consultant has the qualifications in applied behavioral analysis and school consultation necessary to address your child's needs.

☐ 5. The behavioral consultant is part of the team of providers and monitors and provides feedback to me and the staff about program progress and needed modifications.

Parent Involvement

☐ 1. We have discussed concerns about our child's social skills deficits.

☐ 2. We are invited to, and attend, each planning meeting.

☐ 3. Our opinions are solicited and valued at these meetings.

☐ 4. The plan reflects our input.

☐ 5. All parties work toward generalization of our child's skills at school. and at home.

changes in your child's social skills and behavior. A validated curriculum can provide that confidence, focusing on social skills development in areas that include pragmatic language development; flexibility in managing tasks, settings, etc.; attention skills and adaptive behavior.

The materials used to teach social skills should be as similar as possible to materials used in real life—this can result in a greater transfer of skills because the instructor can tailor the lesson to the needs of the student or class. Depending on the assessment results, social skills programming can occur on a daily, multi-day, or weekly basis; its duration should be adjusted based on developmental level, attention span, interest, and maturity level.

Implementing a social skills curriculum

The curriculum may be implemented in many different ways, depending on the needs of the child and the target skills to be addressed. Instruction can be carried out at the district, school, classroom, and individual levels or in some combination; social skills programs can be conducted with whole classrooms, small groups, or on a one-on-one basis.

Often, children will not learn social skills just from being given an opportunity to interact with peers. Like any other skill, children need to be taught what to do—and when to do it.

Teaching Social Skills

There are several different approaches to teaching social skills. Some children learn as a result of incidental teaching. This is when children learn about social skills and how to do them through their own observations of others and the interactions they have with others in their natural environment. An example would be receiving reinforcement from the teacher for demonstrating a particular skill. Other approaches—peer-initiation strategies, peer tutoring—involve a child's peer network. A socially competent peer is paired with a child needing social skills; the goal is to assist the child in developing or refining a particular skill.

Some children can only learn social skills through direct skill instruction. This kind of instruction involves a direct and systematic way of teaching a social skill or behavior and can involve a curriculum that is used to teach various skills. Research has identified the critical features of this approach that will be most effective in bringing about long-lasting change and improvement. Studies have also found that there is a direct relationship between the amount and quality of social skills training and the extent of behavior change.

FEATURES OF DIRECT SKILL INSTRUCTION

Modeling and coaching: Children are shown examples of people (models) performing behavioral steps competently.

Role Playing: Children need to be provided with numerous opportunities to practice new skills.

Performance Feedback and Reinforcement: Children need to receive frequent feedback and positive reinforcement—praise, reward plans—for demonstrating skills to make it worthwhile to use them. The improved behavior must occur frequently enough so that reinforcement can be given. Through this process, chil-

continued on page 36

What Can a Parent Do?

At Home

Look for and find appropriate behavior;
Define and quantify the behavior operationally;
Use reinforcement;
Take advantage of natural opportunities;
Try to ignore inappropriate behavior;
If needed, find a competent behavior analyst to help you;
Look at the long-term;
Prepare for transitions.

At School

Do you know whether your child is making progress? "Show me the outcomes."
Has the school asked you what you think is important for your child?
Have you indicated what are you long-term goals?
What is your child's curriculum?
Ask yourself: "How can I help the educational staff working with my child?"
Attend meetings;
Communicate, COMMUNICATE, **COMMUNICATE!**

continued from page 35

dren should understand why to use the skill and with whom; what skill should be chosen; when and where to use it; how to perform the skill; what to do if the skill is unsuccessful.

Generalization: In order to increase the strength of a social skills intervention, a number of service components should be in place to promote skill acquisition across settings. When a child begins to demonstrate success in using a skill across different settings or with different individuals, generalization of the skill has occurred. Generalization of social skills is improved when programming is conducted in the settings where the skills need to be performed, with different examples and models, involving socially competent peers.

The program should include teaching the difference between appropriate and inappropriate skills and teaching the child self-management of the behavior when possible; efforts should be coordinated with school staff. Transfer training refers to the specific procedures that are designed to help build generalization, such as the teaching setting, materials, personnel, reinforcement systems, and task instruction.

3. Program Monitoring and Evaluation

The third key to developing effective social skills programming is to monitor and evaluate program outcomes to determine whether the intervention is working. This step also involves identifying personnel who will monitor, evaluate, and communicate program progress over time.

The people monitoring behavior should look for instances when the skill is demonstrated, then assess the child's mastery and fluency of usage of the target skills. Data collection can involve both formal and informal observations and assessments using empirically-based rating scales or surveys. Ongoing data col-

With the Creepster Crawler, You Can Watch Your Child Crawl for the First Time!

Children lacking head control, the ability to roll over or belly crawl have gained mobility with the ***Creepster Crawler.*** Using this light, innovative device, hundreds of children around the world are crawling, working more productively with their therapists, and gaining a head start to more advanced mobility in the future.

The ***Creepster Crawler*** is an ideal solution for youngsters with debilitating conditions such as ☐ Spina Bifida ☐ Down Syndrome ☐ Cerebral Palsy ☐ TBI, and ☐ developmental delays. Children with tracheostomies and G-Tubes also are successful users of the ***Creepster Crawler***.

The ***Creepster Crawler***'s frame has a padded platform that can support a parent or therapist from above, making it easier to work with the child on weight-bearing, weight-shifting, reaching and creeping. Front shoulder, chest and rear straps can be adjusted for individual fit.

Please visit our Worldwide Web site at www.red-enter.com for additional details and a video demonstration of the ***Creepster Crawler***.

Call for a Brochure!
1-800-577-1317
Fax:1-602-242-9211
or email us at info@red-enter.com

RedBarn
ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.red-enter.com**

CAUTION: Children should not be left unattended in the Creepster Crawler

Circle #45 or visit www.eparent.com/adinfo

Additional Reading

J. L. Matson. *Handbook of Behavior Modification with the Mentally Retarded.* NY: Plenum Press, 1990.

C. Maurice, S. Luce and G. Green, *Behavioral Intervention for Young Children with Autism: A manual for parents and professionals.* Austin, TX: Pro-Ed, 1996.

D. Rotholz and J. Jacobson. *Behavioral consultants: Who are they and how do I find the right one?* Columbia, SC: Center for Disability Resources, 2001.

lection allows team members to track progress on a daily, weekly or biweekly basis. This level of monitoring can allow staff to quickly identify progress and/or areas in need of improvement in order to ensure the rate of student progress to meet annual goals.

4. Staff Competencies

The final key to developing effective social skills programming is to have staff, support personnel, and case consultants who are adequately trained with the competencies needed to develop, implement, monitor, and evaluate programming. Individuals who provide social skills programming for students with developmental disabilities should be competent in the use of applied behavior analytic procedures.

Applied behavior analysis (ABA) is a highly individualized method of instruction based on scientific principles of learning theory. It is used to design student programs that are implemented systematically, evaluated empirically, and introduced within natural environments. This method has been validated by more than 25 years of research as the most effective way for individuals with and without disabilities to acquire skills, increase socially useful behaviors, and reduce problematic behaviors.

Competencies should include knowledge of:

- Mental retardation, PDD, and other developmental delays;
- Assessment: FBA, social skills assessment;
- Best instructional practices;
- Applied behavior analysis;
- Social skills training;
- Behavior support plans. **EP**

This article has been adapted by the EP editorial staff from a workbook on social skills programming being developed by the Consultation Services Department of The May Institute, Inc. © 2002, The May Institute, Inc.

The May Institute, Inc. is a private, nonprofit organization providing behavioral healthcare, education and rehabilitation. Headquartered in Norwood, MA, with facilities throughout the country, the Institute maintains affiliations with more than 40 universities, hospitals, and human services agencies in the US and abroad. The organization was founded in 1955 by Jacques M. May, MD, and his wife, Marie Ann May, who wanted to provide a progressive treatment and living environment for their twin boys with autism.

For information on The May Institute and its services, check their Web site at http://www.mayinstitute.org or call (800) 778-7601 (toll-free) or (781) 440-0400; TTY : (781) 440-0461. The street address of the corporate headquarters is One Commerce Way, Norwood, MA 02062.

Enjoy the out-of-doors together with a
CycleTote® Bicycle Trailer
Running Stroller
1-800-747-2407 www.cycletote.com
Satisfaction Guarantee/Lifetime Warranty

Safety of your child with a disability

By Cema Mastroleo, MEd, and Wendie H. Abramson, LMSW

Parents want their children to be safe from accidents, illnesses, physical harm, bullying, drugs, etc. In considering our children's safety, preventing abuse is essential.

We have a key role in protecting our children from abuse whether our child has a mild or severe disability. Parents can be proactive in preventing victimization by teaching about personal safety. It is also important to help our kids build awareness of their emotions and personal boundaries.

Teaching our children about personal safety is an ongoing process and following are some suggestions for tackling this issue. These tips can be adapted to your child's learning needs.

Feelings - Discuss feelings (e.g., happy, scared, angry, safe, confused) and provide examples of situations when people may have these feelings.

Touches - Identify various types of touches—touches that are appropriate (e.g., a goodnight kiss from mom, high fives with friends, medical check-ups) and touches that are not okay (e.g., pulling hair or touching other's private parts without permission).

Safety planning with your child – Discuss possible safe ways to respond to hurtful or dangerous situations. Examples include leaving the situation, yelling for help, saying "No!" and telling trusted adults. Have your child identify who they trust.

> If your child uses a communication board or other augmentative communication device, the device may need to be updated with words or symbols for communicating about personal safety.

Rights - Talk to your child about her rights. Allow her to make choices and to tell you "no" sometimes. If someone tries to hurt her, she will have had practice saying "no."

Secrets - Talk about "fun" and "special" secrets. A surprise birthday party is a "fun" secret and is okay not to tell. "Special" secrets are hurtful (e.g., an adult fondling a child and making a threat if the child tells). A child needs to tell trusted adults if someone asks them to keep a "special" secret.

Social behaviors - Teach your child about behaviors that are socially acceptable in public (e.g., shaking hands) versus private places (e.g., changing clothes).

Values – Teach your child about family, cultural or religious values about sexuality and relationships.

Sexuality/Puberty – Discuss the medical terms and functions for all the body parts (including the private parts for males and females). As puberty approaches, talk about normal body changes for boys and girls.

Personal care - If your child needs personal assistance with hygiene at school, check if the bathroom doors close or if there is a curtain around change area. Make sure you and your child are comfortable with staff responsible for your child's hygiene.

School - Ask your child's school to provide abuse prevention, sexuality education and personal safety drills to reinforce the concepts taught at home.

Disclosure of abuse - If your child tells you about abuse, seek medical attention if necessary. Call 911 if there is current danger.

Suspicions of abuse - Report any suspicion of abuse, neglect or exploitation to the local police department and child protective services.

Support - If your child has been abused, consider seeking counseling for your child with a therapist or rape crisis agency. This may help him heal from the trauma.

Communication - If your child uses a communication board or other augmentative communication device, the device may need to be updated with words or symbols for communicating about personal safety. Other possibilities may include a switch with a pre-recorded message, whistle or other personal alarm device for signaling emergencies.

Talk to your child about her rights. Allow her to make choices and to tell you "no" sometimes. If someone tries to hurt her, she will have had practice saying "no"

Personal care providers - When hiring personal care providers, be clear about your expectations, check references, do background checks and offer the employee ongoing supervision and feedback.

Internet - If your child uses the Internet, instruct her not to give personal information to anyone.

Other providers - If your child lives in a group home or institution, get to know the direct care staff and administration. Visit often. Trust your instincts and address your concerns if you think there may be problems.

Modeling - Be a role model by using non-violent discipline.

It is helpful to take advantage of natural teaching moments and to build upon safety information as the child grows and develops (e.g., dating, sexual relationships, managing personal care attendants).

SafePlace's Disability Services offers informational fact sheets and materials on topics related to healthy relationships, sexual health, sexuality education and abuse prevention through its' International Resource Lending Library. Visit: http://www.austin-safeplace.org or call (512) 267-7233 for information. **EP**

Wendie H. Abramson, LMSW is the Director of SafePlace's Disability Services ASAP (A Safety Awareness Program) in Austin, Texas. The statewide program that she oversees offers outreach, abuse prevention education and crisis intervention geared toward persons with disabilities.

Iracema "Cema" Mastroleo, MEd is a Disability Services ASAP educator at SafePlace and provides abuse prevention and personal safety workshops for children with disabilities, their families and professionals. Ms. Mastroleo has over 20 years experience working with children and adults with disabilities in both the United States and Brazil.

RIDE THE LIGHTNING!
PRO LACROSSE AT CONTINENTAL AIRLINES ARENA
A JAYSON WILLIAMS PRODUCTION

STORM NEW JERSEY

Upcoming Home Game Schedule:

Sat Mar 16 Ottawa 8:00pm
Sat Mar 23 Columbus 7:30pm

www.njstorm.com • 1.866.NJSTORM

Circle #41 or visit www.eparent.com/adinfo

Early Warning

Early childhood is a time that is marked with important milestones in development. It is also an opportune, if not critical, time for helping a child with a disability to make improvements in areas where there are deficits. In these articles, two mothers discuss the impact of early intervention and support in their families' experience with apraxia of speech (also known as developmental apraxia of speech, verbal apraxia or dyspraxia), a neurologically based disorder affecting the ability to plan, execute and sequence the movements needed for speech.

Dealing with A Parent's Worst Nightmare

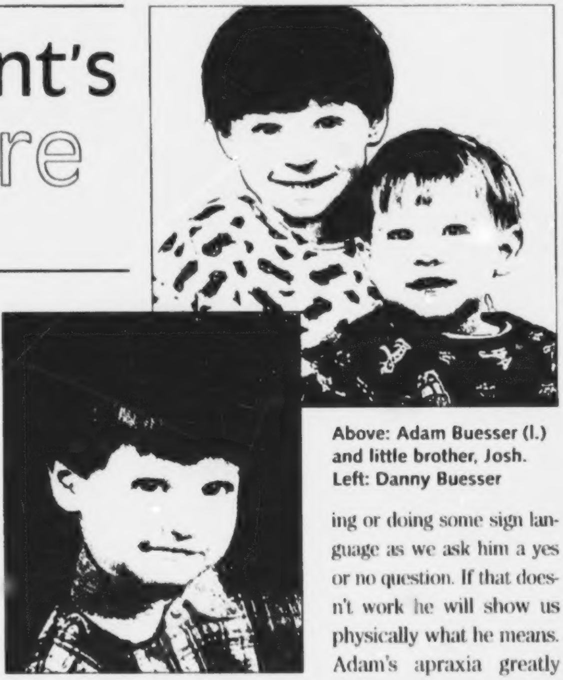
By Jeanne Buesser

When my husband, Raymond, and I chose to become parents, we jumped into the unknown. Our children's well-being and happiness became our concern. The first of our three sons, Danny, was a healthy, very active boy. He was a very independent child, smart beyond his years.

Our second son, Adam, was born 2 1/2 years later. Adam was a big baby like his brother, with no obvious problems at birth, although his tongue stuck out and his cheeks sagged a little. No one thought there was a problem, except that Adam never babbled or made sounds as an infant. We just thought he was a quiet child.

How quickly life can change, though. When he was a little more than 3 1/2, Danny contracted Burkitt's lymphoma, a rare fast-growing cancer with few symptoms. This virtually silent killer took the life of our son within hours of his diagnosis. We were devastated, in shock, unable to comprehend how we as parents couldn't save our child. We asked, "Why did we deserve this? Why us?"

Ten days after Danny died, I joined a group called The Compassionate Friends, a bereavement support group for parents experiencing the death of a child. It was the one place I felt I could express my grief and lean on others who had similar tragedies. I learned the benefit of being with others who could share ideas for living. I became the librarian and facilitator of my local chapter. I discovered that whatever positive support and energy you give to others will return to you three-fold.



Above: Adam Buesser (l.) and little brother, Josh. Left: Danny Buesser

A new start, more challenges

In our grief, we weren't overly concerned that Adam still wasn't talking; we were trying to deal with Danny's death. Wanting to make a new start, we sold the house and moved to another. It wasn't until Adam was 2 years old that a neurodevelopmental pediatrician diagnosed him with a neurological speech disorder called apraxia of speech.

Children with apraxia of speech are unable to produce the sounds for speech so as to be understood, despite having the ability to do so. Intelligence level in most children with apraxia is unaffected. For example, Adam can put together 60-piece puzzles without ever having seen them before. He has a picture-perfect memory, and can approximate the picture to the puzzle box. But it is also very frustrating for him. Adam will have tantrums because he can't respond to our questions with intelligible speech. Adam makes his needs known by pointing or doing some sign language as we ask him a yes or no question. If that doesn't work he will show us physically what he means. Adam's apraxia greatly limited his circle of friends. No one could understand what he wanted and few children wanted to play because he was "different."

For Adam, as for most children with apraxia, intensive speech therapy was key in helping him once apraxia was diagnosed. Occupational therapy was also necessary.

His intensive speech therapy is three to four times a week and includes brushing his tongue with a toothbrush; trying to get him to blow bubbles, blowing through straws, blowing candles out; getting him to pucker his lips, trying to repeat the sounds p, b, m, d, and others, to strengthen and coordinate his facial and mouth muscles. The therapist recommended massaging his cheeks to tone his muscles.

Adam now says up to 80 words. We don't always understand him because he cannot produce some of the syllables/consonants of speech. When the therapy first began, the only sound that he could say was "mmmm."

A few months ago, our family had a frightening experience when Adam got lost while we were on an outing at a large zoo. It taught us an important lesson. I have since gotten an ID bracelet for Adam, since he cannot speak his name or give a phone number or ask for help himself.

Apraxia of speech is an often overlooked disorder with no known cause. In defining developmental apraxia of speech, the American Speech-Language-Hearing Association (ASHA), describes its effect as: "The child knows what he or she wants to say, but the brain is not sending the correct instructions to move the body parts of speech the way they need to be moved."

Adam is now 6 years old and attends a special education kindergarten class for speech. He writes his name and uses a special computer device to help him communicate. His speech is slowly getting better. Sometimes it is very fast and gets garbled.

As a parent, I cannot stress how important it is to educate medical professionals, teachers and parents about apraxia. When Adam was diagnosed with apraxia I didn't know where to turn for help. If more professionals knew about this disorder, many more parents of diagnosed or undiagnosed children would know there is hope and information that can help them.

Many parents whose children don't talk by age 2 or 3 may not think there is a problem. I was reminded of that by relatives. They counseled, "The child will talk when he is ready, don't worry." If the child isn't diagnosed and doesn't have intensive therapy early, valuable time may be lost and the speech patterns can be very hard to correct. As the child gets older, other problems can arise.

Gaining strength from support

How did I learn more about apraxia? A relative sent me a newspaper article about apraxia and a support group here in New Jersey, the C.H.E.R.A.B. Foundation, headed by Lisa Geng. Lisa had also founded the Children's Apraxia Network since her son, Tanner, had been diag-

continued on page 43

C.H.E.R.A.B. Foundation

C.H.E.R.A.B. (Communication Help, Education, Research, Apraxia Base) Foundation is a nonprofit organization whose goal is to improve the health and welfare of all children with speech delays and disorders, with a special focus on apraxia or other severe neurologically based speech conditions. The group describes the "cornerstone" of their efforts as bringing "professionals from different disciplines together to provide the most comprehensive evaluations and treatments for these children."

The Foundation, with the help of the Consortium for Fatty Acids, Omega-3 Research Institute, Inc., held the first conference for therapy of verbal apraxia/dyspraxia, "Verbal Apraxia/Dyspraxia and Essential Fatty Acid (EFA) Supplementation: A New Potential Therapeutic Intervention" in July 2001. According to Lisa Geng, president and founder of C.H.E.R.A.B., "We are currently exploring working with one of the leading teaching/research hospitals here in New Jersey, which has shown an interest in coordinating clinical trials involving the use of essential fatty acids (particularly omega 3 and 6) in children with severe multi-faceted speech/communication disorders." Says Geng, "We are all very excited about the tremendous potential this research would hold for our children's future to help bring them a voice."

Evan's Story

by Stacey Abenstein

The question that everyone seems to ask me is, "How did I know there was a problem at such a young age?" My son Evan is our second child. As an infant, he babbled normally. When Evan didn't have any words by his first birthday, we didn't panic. We tried not to compare him to our first child, Carly, who seemed to be born talking and has always been very advanced. When Evan started saying a few words at 15 months, we were thrilled. Those words had simply vanished at 18 months! People tried to tell us that boys talked later, and that Einstein didn't talk until he was 5. I knew in my gut that there was something wrong.

A very dear friend who is also a neurodevelopmental pediatrician sat down with Evan at a barbeque, and determined that Evan had a severe delay in expressive language, but at 20 months, was at or above age level in ALL other aspects. He handed me the number for Early Intervention, and the quest for answers began.

Early Intervention evaluated Evan at 21 months and determined that his expressive language was at a 15-month level. We started speech therapy at 22 months. The therapist started with the "withholding" approach. We would model the word "pretzel" and Evan would have to repeat the word to get the pretzel. Evan got so frustrated he kicked me in the shins! He could not imitate a hand motion, let alone a sound. After a week or so of this, the speech therapist realized a different approach was needed. She suggested that Evan had apraxia of speech. I made her spell it, and I hit the Internet before she

Evan loves his sister.

continued on page 42

Evan's Story Continued

pulled out of the driveway. After all the research I did, all I could do was cry!

I followed up the therapist's diagnosis with a hearing test and a trip to another neurodevelopmental pediatrician that my friend had recommended. Apraxia of speech was confirmed. And so started our journey to remediation.

We upped the EI speech therapy to twice a week and had an occupational therapist evaluate Evan next. We discovered that Evan had sensory integration dysfunction. Just an added bonus! I read on the Apraxia-Kids LISTSERV that it is common for this combination to be present. With the occupational therapy in place, we trudged on. Evan was asked to leave his preschool at 26 months. He had been hitting or, as I called it, "communicating with his hands." We replaced preschool with gymnastics and swimming, as the gross motor activities produced the sensory input Evan needed. The hitting continued, but we could never predict when it would happen.

When he was 30 months old we felt that Evan needed more. We added a session of private speech therapy and temporarily replaced OT with a group speech/OT session given in a preschool environment. Evan's speech exploded! He went from 40 to 100 words/approximations in about a month! He also started to combine two words, which requires more motor-planning than he had ever been able to accomplish!

We have him attending twice a week a very small, home-based toddler program, with normally developing children, that he absolutely loves! He doesn't seem to be any more aggressive than any other 2-year-old boy in this setting. We had determined that his aggressive behavior gets worse as the number of children increases, so we were careful to select a program that was small enough to meet his needs.

It has been a very tough year! There were times that I felt like a shut-in, never leaving the house in fear that Evan would hit other kids in frustration. There were times that I felt that the hitting must be due to bad parenting. Although I know in my heart we are doing everything we can for Evan, I can't help but blame myself for not always having as much patience as I should. And what about the future? The prospects of further learning disabilities, as stated by the experts' statistics, scare me to death. We will just have to take it one day at a time.

While looking for more information and support, I stumbled upon the Children's Apraxia Network. My EI SLP came with me to my first meeting. While I am generally not a group kind of person, I found the information disseminated invaluable. I also felt a kinship with the people attending the meetings, as no one else I knew had a child with apraxia. I have since agreed to become the group's secretary and have been known to be seen taking the minutes in crayon!

While my original objective for becoming part of the group was totally selfish, the roller coaster ride has brought me to a point of wanting to help other parents in line for the ride.

Update

Now 4, Evan is doing extremely well. He identifies all the uppercase letters and most of the lowercase as well. He knows his address and phone number. He writes his name better than most kindergartners. He spent last summer at regular day camp, three full days per week. It was a huge self-esteem builder for Evan and his connected speech improved as well. He is still difficult to understand at times, but he can usually get his point across.

He attends two preschool programs—Pride, the district's preschool special program, as well as a regular preschool—and is succeeding in both. At school, Evan also receives individual speech therapy twice a week and group therapy once a week. To address his sensory integration needs, he receives one individual occupational therapy session and a sensory motor group.

He will attend camp once again this summer, this time with his sister. He will be fine, in fact, he will have an even better time, as the camp has even more to offer than last year's camp. But I will probably worry all summer! EP

HDIS

Convenient Home Delivery of Bladder Control Products

Try Tranquility® All-Through-the-Night Disposable Briefs, FREE!

FREE Sample Offer!

More absorbency means more comfort and protection.

- Extraordinary absorption capacity.
- No need for multiple changes through the night.
- Latex-free construction.
- Wide range of sizes (including youth) to assure a comfortable fit.

Call now for a FREE sample!

1-800-2MY-HOME®

(1-800-269-4663)

"We're here to help make your life a little easier."

- *Mary*

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

©2002, HDIS

024-126

Circle #31 or visit www.eparent.com/adinfo

Worst Nightmare Continued

nosed with apraxia. After talking to Lisa, attending the Foundation's meeting and feeling inspired by the help I received through The Compassionate Friends, I decided to start a support group in my area.

Though we are without Danny, my family lives on with Adam and Josh, who is almost 3. I hope someday Adam and Josh will ask about their brother. Josh is speech delayed and has been diagnosed with pervasive developmental delay (PDD) with autistic tendencies. The comfort and help that we get from our support group is extremely beneficial to us and also encourages us to help others. **EP**

Jeanne Buesser is the President/Founder of the Apraxia Network of Bergen County, NJ (Web site: http://community.nj.com/cc/apraxianetworkofbergencounty).

Tips from Jeanne for starting a support group

- Find a public place to meet.
- Write a press release—who, what, where, when and why—to help promote your group, to be placed in as many local papers as possible.
- Find relevant articles for eventual distribution to other parents.
- Start a Web page, if possible.
- Maintain a contact list with names, phone numbers, addresses and e-mail.

Resources

ASHA
10801 Rockville Pike, Rockville, MD 20852
(800) 638-8255 • http://www.asha.org

C.H.E.R.A.B. FOUNDATION
657 Valley Rd., Box 339, Gillette, NJ 07933
(908) 626-5437 • http://www.apraxia.cc

Childhood Apraxia of Speech Association of North America
123 Eisele Rd., Cheswick, PA 15024
(412) 767-6589 • Fax: (412) 767-0534
http://www.apraxia.org
http://www.apraxia-kids.org

The Compassionate Friends, Inc.
P.O. Box 3696, Oak Brook, IL 60522-3696
(877) 969-0010 • (630) 990-0010
Fax: 630-990-0246
http://www.compassionatefriends.org

One of a kind

There are no formulas at Heartspring, just ongoing dedication to helping children with multiple disabilities achieve their fullest potential. Our multi-disciplinary approach recognizes each child as an individual and provides a plan customized for their specific needs. Your child is one of a kind. Why should their education be anything less?

Call today to learn more about a school unlike any other.

1-800-835-1043

Heartspring School
Finding New Ways for Learning

8700 East 29th Street North · Wichita, Kansas 67226 · www.heartspring.org

Circle #19 or visit www.eparent.com/adinfo

This month, EP is honored to introduce its readers to Dr. Jan Blacher who will contribute a regular column on research in the area of family and disability: *Research Reflections*. Dr. Blacher received her AB from Brown University, and her PhD from the University of North Carolina at Chapel Hill. She has been a Professor in the School of Education at the University of California, Riverside, since 1979, where she teaches a course on exceptional children required of teachers in California; she also teaches and trains masters and PhD students in research on exceptionality. Dr. Blacher's own research has had a parent/family focus for the last 25 years. She is principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities that has been ongoing since 1982. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of retardation, dual diagnosis, and the transition to adulthood. Due in part to the encouragement of her own research families, Dr. Blacher has developed *Research Reflections* as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to *Research Reflections* and any suggestions you might have. Send email to: jan.blacher@ucr.edu.

CONFESSIONS OF A RESEARCHER: Blind Alleys, Unintended Consequences and Really BIG Mistakes

by Jan Blacher, PhD

I remember a birthday gift that my older brother got when I was in preschool—a really huge Pink Pearl eraser that had the words, "I never make BIG misteaks" printed across it. By the time I was old and schooled enough to get the joke, I had already made plenty of my own.

Before I can comfortably commence as your resident researcher and author of "Research Reflections," I have a few confessions to make. The first is that I wear my heart on my sleeve—you'll always know where I'm coming from. When I was asked to write this column for Exceptional Parent (EP), I was excited. I had been working with and studying parents since graduate school, but the pressure was always "on" to publish in the most scientific (read: esoteric, ivory tower) journals. After 20 + years of this, it is time to communicate with the readers I care most about.

I'll start off confessing one really big mistake—believing everything I read about parents of exceptional children. The literature we were assigned in graduate school evoked images of Edvard Munch's etchings—depressed, sad faces of stressed-out parents and families. In a subsequent column I will review 100 years of this literature on families and disability for you; suffice it to say here that challenges were emphasized over triumphs, negative impact and stress over positive contributions. I was led early on to expect to find great family distress. After almost 20 years of studying large numbers of families who have children/young adults with severe disabilities, I have learned that the best word to describe these parents is resilient. They have withstood the fickle winds of social policy and practice regarding their children (from advice to "place that child into an institution and forget about him," to "all children with disabilities belong with their families," to "young adults with mental retardation should be living and working independently in the community.") And, in addition to dealing with ongoing or newly appearing behavior problems or medical concerns, they have had to contend with the arrogance, stubbornness or insensitivity of service providers and professionals. If that isn't resilience, then what is?

Researchers' dilemmas are not always about really big mistakes, however; sometimes we just find ourselves traveling up a blind alley, as we did in some of our earlier studies of family coping. Since 1982, we have been interested in what factors help parents to keep a child with very severe impairments at home, and what factors influence out-of-home placement. We hypothesized that a lack of "attachment" between parent (mainly mother) and child would increase the likelihood of placement. This was based, in part, on a review that my friend and former mentor, Ed Meyers, and I published in 1983. Furthermore, we hypothesized (based on all that accumulated literature) that once a family placed a child, family members would soon "detach." Detachment (or "out of sight, out of mind") would be evident by lack of visitations and phone calls to the child/caregiver, for example. Our hypotheses apparently seemed reasonable to the federal agency that funded the project. It turned out that not only did mothers express and exhibit strong attachment to their children (behaviorally and as reported on questionnaires or in interviews), but also that this attachment was a primary reason that families did not place sooner. In no case did a family place because of lack of attachment.

In order to study "detachment," we embarked on a series of studies of families who had recently placed their son or daughter. These studies included several hundred families whose children were in residential facilities in California, Arizona, Massachusetts, or Florida. In one study, Bruce Baker, Kristin Feinfield and I interviewed 53 families three times, an average of 1, 2, and 3 1/2 years following placement. Parental visitation remained high across these time periods, with 83 percent of families reporting some type of visit at least monthly by the end of 3 1/2 years. Expressed attachment was high and stable, and most parents reported experiencing less guilt than at the time of placement. Parents were still thinking and talking about the child frequently. In additional studies, using other families, we also found little evidence for detachment. Parents' level of involvement with their children right after placement was highly predictive of their involvement 3 1/2 years later. Furthermore, in a series of studies we have discovered that parents' own adjustment post-placement, and their perceived well-being of their family, was very high following placement. In sum, the attachment-detachment theory in this case did lead me down a blind alley, but in its pursuit I arrived with further evidence of parents' resilience.

And then, sometimes to a researcher's dismay, there are unintended consequences. Another aspect of family coping that has been of interest to researchers, practitioners and families alike is "support." As you well know, support for families can take many forms, and trying to assess parents' knowledge of, use of, and satisfaction with support has posed real research challenges. In our studies, we have been concerned most with formal support (services provided by the public schools, regional centers or state agencies, or the federal government) and informal support (mainly from friends or other family members). One clear intention of such support was to increase the well-being of families, reduce stress and, for some, prevent the likelihood of costly out-of-home placement. Ironically, we found that the more formal support (especially respite) that parents of children with severe retardation had, the more likely they were to consider, and eventually follow through with, out-of-home placement. Such unintended consequences were, at first blush, alarming and puzzling to us.

Upon further inspection, the notion that the more supports parents had, the more they wanted seemed reasonable. For one thing, the number and intensity of services were related to the child's behavior; low adaptive skills and high maladaptive behavior became a formula for family support need. However, we found that service providers couldn't understand why, after disseminating the contents of their "little black bag" of social supports, parents requested more and more, and then went on to seek out-of-home placement anyway! We realized that their delivery of all those service "goodies" came too late—after families had made the decision to seek out-of-home placement, after they had shopped around for placements, and after they had decided they couldn't take the stress any more. As researchers, it became our job to inform service agencies that they needed to provide meaningful support to families who have children with severe disabilities and maladaptive behavior as early as possible, before there is so much stress that a family crisis occurs.

As a researcher, I have never found a really big pink eraser to wipe out my mistakes—but being alert to them has taught me much. What I hope for is more opportunity to reflect on findings from the field—both good and bad—and the wisdom to know the difference.

These studies I refer to have been funded by the National Institute on Child Health and Human Development (NICHD) of the National Institute of Health. While each particular grant since 1982 addressed different issues across the lifecycle of families (e.g., parents' perception of schooling; the correlates and consequences of placement; adolescence and lifespan concerns; the transition to adulthood) together they comprise what is known as the University of California, Riverside (UCR) Families Project. The Project began in 1982 with 100 families who had children with severe disabilities, then between the ages of 2 and 9 years. Today, I am still studying the original group of families, plus hundreds of others who became participants during follow-up waves of the study.

EDITOR'S NOTE: A list of the studies offered by Dr. Blacher may be obtained by e-mailing requests to: epedit@aol.com.

How did your family cope with disaster?

Project Cope

Project Cope is a national clearinghouse for resources related to trauma recovery, with an emphasis on special and vulnerable populations, including individuals with disabilities. With the support of the federal Administration on Developmental Disabilities, the Westchester Institute for Human Development developed Project Cope to meet the unique coping needs of children and adults with disabilities in the wake of the September 11th events. This is the third in a series of EP articles about trauma and its effects on children with disabilities and their families.

September 11th and its aftermath

The terrorist attacks of September 11th opened a new chapter in American history. The September 11th attacks began several months of stress and uncertainty. Throughout this, families have remained committed to minimizing the impact of these events on their children.

Our first two coping guides

Last fall, EP featured two articles about disaster and coping. In these articles we advised families on how to cope with trauma. In our first coping guide (November 2001), we outlined some expected reactions in children and provided general suggestions to help children cope. How children cope is closely related to how their families are coping. Thus, our second coping guide (December 2001) focused on parent reactions to trauma.

Taking stock: The Project Cope – EP Family Survey

Following the September 11th attacks, we heard from and worked with many families of children with disabilities. Reactions in those families varied greatly. The parent of a child with severe autism shared her story with us: her child knew little about the events themselves, but old behavior problems reemerged due to the stress the whole family experienced. In another family, Heidi, an eight-year-old girl who uses a walker, told her mother she was afraid she'd 'never get out of her school' building if there were a disaster. Maria, age four, reacted by becoming withdrawn. Cassandra, three, lost her mother on September 11th and will not go to nursery school without her father. Jake, age twelve, became obsessed with details of the disaster and subsequent cleanup. His preoccupation is just now beginning to wane.

Stories shared by these and other families provided information that helped shape our coping guides. Now, we'd like to take stock from a broader perspective. How did children, especially children with disabilities, react to the events of September 11th? We need your help to answer that question. With the support of EP and the Administration on Developmental Disabilities, Project Cope is conducting a national survey, seeking information from families about the impact of these events on children with disabilities. The field of trauma studies is well developed, yet there is little information on how families of children with disabilities might be uniquely affected. The goal of this research is to learn more about children and trauma. Your responses will better our understanding of how to help children, particularly children with disabilities, cope with trauma.

Tell us by participating in the Project Cope—EP Family Survey.

Completing the survey

Please consider responding to this survey (found on pgs. 49-50). Either complete the form on the next page and mail it back–the survey is postage-paid and does not require a stamp–or log on to our web site, http://www.ProjectCope.net. In the first part of the survey we ask about your family and how directly you were affected by the disasters. In the second section we ask you to tell us about your children and how they reacted. We are specifically interested in learning more about children with disabilities, so please answer first about your child or children with disabilities. Then, if there is room, tell us about the reactions your other children had. In the final section, please share any comments or stories that will help us understand how your family reacted to the disaster.

Your participation is voluntary, confidential and anonymous. You must be age 18 or older to participate. Any results we report will be summary in nature and will not include any identifying characteristics. If you are in distress, or if completing the survey is too difficult, please consider seeking help from a mental health professional. Call or e-mail Project Cope and we will be glad to help you locate supports in your area. Look for survey results in a future issue of EP.

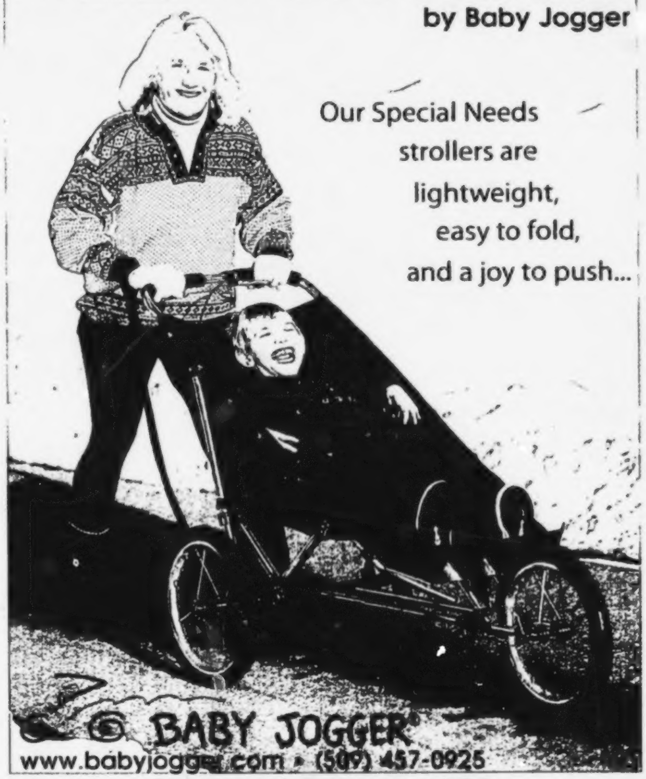
This survey was developed by Project Cope of the Westchester Institute for Human Development (WIHD), a University Center for Excellence in Developmental Disabilities, Education, Research and Service. WIHD is located at Westchester Medical Center and NY Medical College in Valhalla, New York. Project Cope is funded through a grant from the Administration on Developmental Disabilities, Administration for Children and Families, US Department of Health and Human Services. The content does not reflect the position or policy of the agency and no official endorsement should be inferred.

This survey was developed by the Directors of Project Cope, Daniel Crimmins and Anne Farrell, with the assistance of Jonathan O'Brien, Jillian Mattessino, Alison Bailey, Suzanne Busby, Monica Feinberg, Dana Leonardi, Elizabeth Diaz and Jeanne Nessebroth. Project Cope materials, including this survey, may be copied and disseminated without specific permission as along as they are reproduced verbatim, credit the authors and include contact information for Project Cope:

Project Cope / WIHD
338 Cedarwood Hall
Valhalla, NY 10595-1689

✉ ProjectCope@nymc.edu
✆ (914) 493-5202

continued on page 49


The BEST strollers in the WORLD!
by Baby Jogger

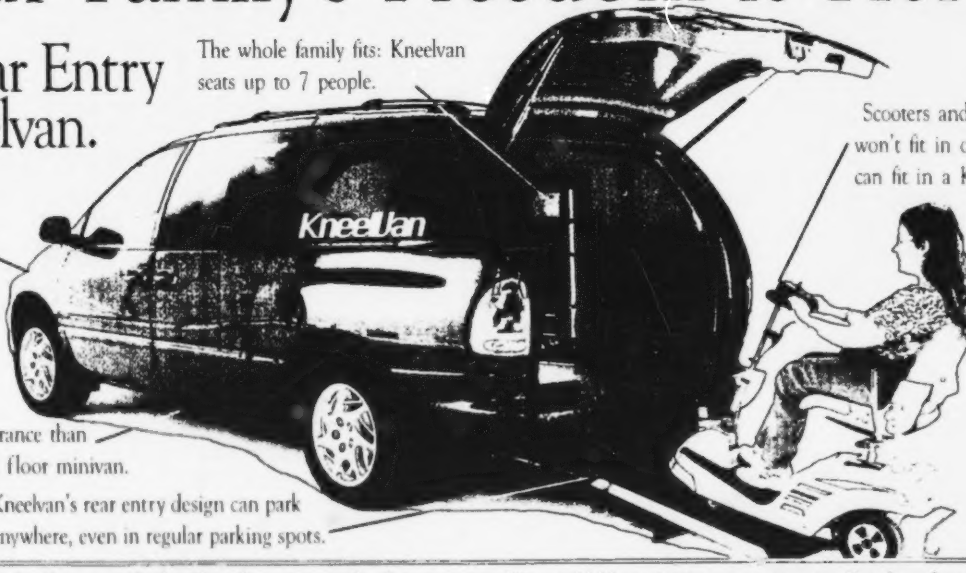
Our Special Needs strollers are lightweight, easy to fold, and a joy to push...

BABY JOGGER
www.babyjogger.com • (509) 457-0925

Circle #53 or visit www.eparent.com/adinfo

Your Family's Freedom is Here:

The Rear Entry Kneelvan.



The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel.** Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #29 or visit www.eparent.com/adinfo

THE MELMARK SCHOOL

2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Our approved private day and boarding school serves children ages 5-21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Acquired Brain Injuries
- Cerebral Palsy
- Mental Retardation
- Neurological Disorders

Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

We Offer Your Child:

- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK Ext. 636 or email admissions@melmark.org

Circle #40 or visit www.eparent.com/adinfo

We Like Making Kids Happy...

Send For Free Catalog

equipment shop

P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax: (781) 275-4094
www.equipmentshop.com

Circle #27 or visit www.eparent.com/adinfo

SUREHANDS®

Anchors in different locations when needed.

Gary L., accountant, Warwick, NY - Becker's MD

At last, a Lift & Care℠ system as versatile as a pair of hands...and portable, too.

It's a motorized transfer device,
a positioning tool *for posture seating*,
a bathing support,
a hygiene helper *for toileting or diapering*,
a floor space-saver,
a standing support *for some*,
a dressing assistant,
and a back-saver *for carers*.

SUREHANDS LIFT & CARE SYSTEMS

Portable and permanent solutions for homes and workplaces.

1-800-724-5305

e-mail info@surehands.com • website www.surehands.com

Circle #52 or visit www.eparent.com/adinfo

Parent Survey on the impact of September 11th on children

This survey asks about your family's reactions to the terrorist attacks of September 11th. We are most interested in the experiences of children under the age of 18, particularly those with disabilities. If you have more than three children, please complete the survey for your child with a disability and his or her siblings closest in age. This survey is part of a research project; your participation is totally voluntary and completely confidential.

TELL US A LITTLE ABOUT YOUR FAMILY **Today's date** ___ /___ /___

Who lives in your home? Number of parents ________ Number of children _______ Number of other family members _____

Person completing the survey: ☐ Mother ☐ Father ☐ Other Your zip code ____________

How directly was your family affected by the September 11th attacks? ☐ Not at all ☐ A little ☐ Some ☐ A lot

To what degree was your family affected economically by the attacks? ☐ Not at all ☐ A little ☐ Some ☐ A lot

How much were your family routines disrupted in the first week after the attacks? ☐ Not at all ☐ A little ☐ Some ☐ A lot

To what degree has your family life returned to normal? ☐ Not at all ☐ A little ☐ Some ☐ A lot

What were your major sources of support following the attacks? (check all that apply) ☐ family ☐ friends ☐ community ☐ co-workers ☐ faith ☐ mental health professionals ☐ support group ☐ learned about trauma ☐ learned about coping

Did you read our coping guides in EP? ☐ Yes ☐ No—If yes, how helpful were they? ☐ Not at all ☐ A little ☐ Some ☐ A lot

Did you visit the Project Cope web site? ☐ Yes ☐ No—If yes, how helpful was it? ☐ Not at all ☐ A little ☐ Some ☐ A lot

TELL US ABOUT YOUR CHILDREN	**Child 1**	**Child 2**	**Child 3**
How old is this child in years and months?	___ years ___ mos.	___ years ___ mos.	___ years ___ mos.
Is this a son or daughter?	son / daughter	son / daughter	son / daughter
Does this child have a disability?	yes / no	yes / no	yes / no
If this child has a disability, what is it?	__________	__________	__________
In what ways did your children experience the attacks?		(CHECK ALL THAT APPLY)	
lost a family member or friend	☐	☐	☐
directly witnessed the attacks	☐	☐	☐
visited one of the rescue/recovery sites	☐	☐	☐
watched on television only a few times	☐	☐	☐
watched TV coverage regularly over the first weeks	☐	☐	☐
saw articles or pictures in newspapers and magazines	☐	☐	☐
discussed with family or friends	☐	☐	☐
discussed in class with teachers	☐	☐	☐
What did each child do following the attacks?		(CHECK ALL THAT APPLY)	
attended memorial or prayer service	☐	☐	☐
read or heard stories about heroes of the disaster	☐	☐	☐
donated money or other goods	☐	☐	☐
volunteered	☐	☐	☐
sought reassurance	☐	☐	☐
demonstrated patriotism (e.g., displayed the flag)	☐	☐	☐
drew pictures, wrote stories or letters	☐	☐	☐
reenacted the events through play	☐	☐	☐

What reactions did each child show in the first week after the attacks and in the week just past?			(CHECK ALL THAT APPLY)			
	First week	Past week	First week	Past week	First week	Past week
expressed fear for self or family	☐	☐	☐	☐	☐	☐
showed increases in problem behavior	☐	☐	☐	☐	☐	☐
experienced sleep problems	☐	☐	☐	☐	☐	☐
appeared sad or troubled	☐	☐	☐	☐	☐	☐
seemed jumpy or irritable	☐	☐	☐	☐	☐	☐
had difficulty getting along with family or friends	☐	☐	☐	☐	☐	☐
unable to carry out regular home or school activities	☐	☐	☐	☐	☐	☐
didn't feel well, stomach aches, headaches, fatigue	☐	☐	☐	☐	☐	☐

COPING WITH DISASTER

COMMENTS: Please tell us how your family was affected by the events of September 11th. Share initial reactions and how they changed over time. Include specific changes you observed in yourself and your children, as well as things your children said or did. If you have a child with a disability, do you think these events affected her or him in unique ways? Use additional paper as needed.

☐ Please check this box if we can share your story without revealing any personal details.

FOLD FIRST ALONG THIS LINE

THANK YOU for completing this survey. Please return it to the address below or fax to (914) 493-1973.

The survey may also be completed online at www.projectcope.net.

If you have any questions, please contact us at (914) 493-5202 or by e-mail at projectcope@nymc.edu.

Stress reactions usually decrease within four to six weeks of a traumatic event. For the September 11th attacks, this has been complicated by the extended rescue and recovery period, the anthrax letters, the continuing threat of terrorist acts, and the war in Afghanistan. By this time, most people who were not directly affected by the trauma should be experiencing few reactions. Individuals directly affected may be experiencing an array of reactions. If either you or one of your family members is still having intense reactions, consider consulting a mental health professional. Call or e-mail **Project Cope** if you would like help locating a professional in your area. Our web site (www.projectcope.net) has a great deal of information about the recovery process, as well as what to look for in a therapist (also available in the November and December editions of **Exceptional Parent** magazine). The **Project Cope** website also includes links to many professional and community organizations with disaster-related information.

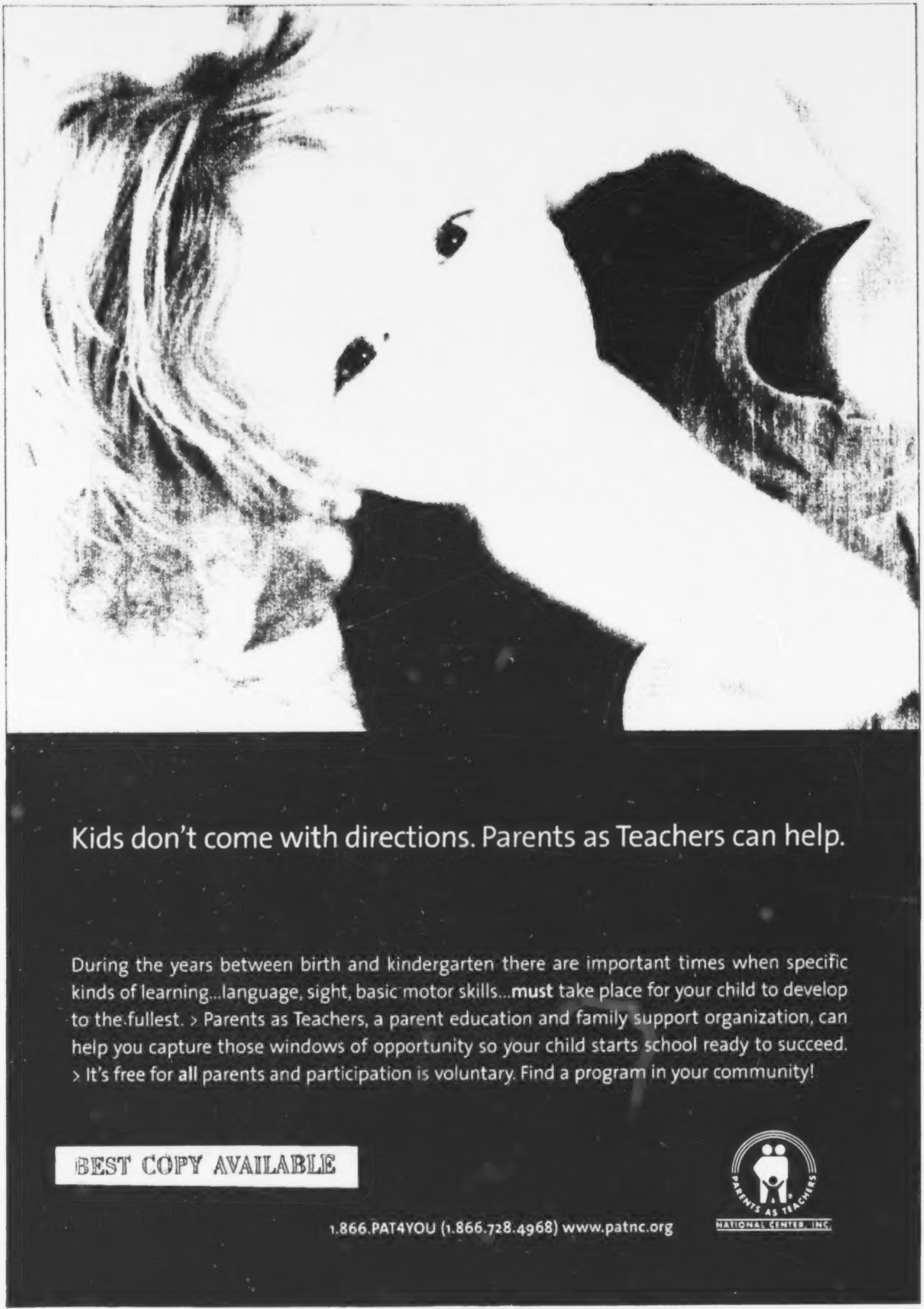
FOLD ALONG LINE BELOW SO THAT ADDRESS FACES OUT. SEAL WITH TAPE.

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 9 VALHALLA NY

POSTAGE WILL BE PAID BY ADDRESSEE

PROJECT COPE
CEDARWOOD HALL RM 338
WESTCHESTER MEDICAL CENTER
95 GRASSLANDS RD
VALHALLA NY 10595-9987



Kids don't come with directions. Parents as Teachers can help.

During the years between birth and kindergarten there are important times when specific kinds of learning...language, sight, basic motor skills...**must** take place for your child to develop to the fullest. > Parents as Teachers, a parent education and family support organization, can help you capture those windows of opportunity so your child starts school ready to succeed. > It's free for **all** parents and participation is voluntary. Find a program in your community!

BEST COPY AVAILABLE

1.866.PAT4YOU (1.866.728.4968) www.patnc.org

PARENTS AS TEACHERS
NATIONAL CENTER, INC.

Universal Newborn Screening

In 1961, Dr. Robert Guthrie of the University of Buffalo developed a laboratory test to detect phenylketonuria (PKU) in newborns. PKU is an inherited metabolic disorder resulting from an enzyme deficiency; if left untreated, it results in profound mental retardation. In 1963 Massachusetts became the first state to mandate screening for PKU, which can be treated by lifelong dietary management and counseling. The National Association for Retarded Children (now The ARC), the Children's Bureau and the Kennedy Foundation were foremost among the organizations that pushed for widespread adoption of the Guthrie test, and by 1966 it was required for all children by all 50 states and the District of Columbia.

Dr. Guthrie and other researchers continued to develop newborn screening (NBS) tests to detect many more disorders, and each state decided what screens would be available for its newborns. Significant disparities resulted; in 1997, in Massachusetts, infants were tested for 10 or more disorders, while Utah's babies were screened for three. Montana and South Dakota each mandated three tests and offered one other by special request only. In the same period, with the introduction of ever-smaller and more powerful microprocessors, technology and equipment became significantly more sophisticated. This permitted testing that had not been feasible before. A process called tandem mass spectrometry (tandem MS, MS/MS) can now run tests for nearly 40 disorders at one time. None are curable, but all are treatable.

In the last two years, many states have expanded their NBS programs. Almost all Pennsylvania hospitals now offer the full spectrum of testing, although the law mandates testing for only six. Massachusetts routinely screens for more than 15 disorders and is running a pilot program offering 30+ tests. Wisconsin has almost tripled availability, from 7 tests to 20. Yet universal NBS still engenders much controversy, and there are many issues to be resolved before consensus can be reached on how the US will move forward.

The data tells us that of the four million babies born in the US each year, ten to twelve thousand may have one or more of these detectable...and treatable...disorders

ISSUES: These may be economic, political, professional, sociocultural, religious. Capital spending, training, payment policies, long-term follow-up; insufficient hard financial data; union issues; professional knowledge levels and practice habits; citizen knowledge, and cultural and religious beliefs and practices; insurance, managed care companies, Medicaid, ChIP programs, the uninsured–all these and many more must be part of discussions and resolution.

With the current system, a child born in Louisiana with galactosemia will likely live a life marked by mental retardation and other special health care needs, while similarly affected children born the same day in most of the rest of the country will receive immediate treatment and become productive members of society. The data tell us that of the four million babies born in the US each year, ten to twelve thousand will have one or more of these detectable disorders, an almost-negligible number. The overall cost or benefit to our society, though, will vary wildly from one child to another because of the patchwork of screening availability. We as a nation must find a way to embrace universal NBS and make it routine for all children born in the US. More than that, it is downright wrong not to do so when it has proven its worth time and again!

It is a question of education and awareness. Research shows that the average couple planning to have children does not know anything about existing screening programs, much less the capabilities offered by tandem MS, largely because OB/GYNs, pediatricians, genetic counselors and related professionals are not familiar with universal NBS. The education gap relates to professionals and consumers, rich and poor, people of every race, religion and ethnicity. Few people know much about any of the issues. Worse, among the people who do profess knowledge of NBS and the issues, a good deal of what they "know" is wrong.

The information you need on Newborn Screening is finally available on DVD and video

CHILDREN AT RISK
The State of Newborn Screening
DVD
VHS
Only
$69.95
PLUS SHIPPING & HANDLING

Children at Risk:

The State of Newborn Screening

is now available on DVD and VHS. Introducing the first in a series of special educational programs presented by EP and the EP Foundation for Education, Inc., a 501(C)3 Not For Profit Corporation.

EP Foundation for Education, Inc. **Child Neurology Society** **EP**

Newborn screening can detect up to 39 metabolic disorders from one blood spot. All are treatable when diagnosed at birth, offering the chance for a full and productive life.

Leading medical and scientific professionals are gathered to provide the most current information available. You can view this valuable resource at your convenience and the DVD is indexed so that key topics are easily accessible.

Darryl DeVivo, MD
SIDNEY CARTER PROFESSOR OF NEUROLOGY
COLUMBIA UNIVERSITY

Piero Rinaldo, MD, Ph.D.
DIRECTOR, BIOCHEMICAL GENETICS LABORATORY
MAYO CLINIC

Edwin Naylor, Ph.D.
PRESIDENT
NEOGEN SCREENING, INC.

Joan E. Pellegrino, MD
ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES
UMDNJ, ROBERT WOOD JOHNSON MEDICAL SCHOOL

Paul M. Fernhoff, MD
MEDICAL DIRECTOR
EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA MasterCard CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #34 or visit www.eparent.com/adinfo

Gynecological and Reproductive Services FOR Teenage AND Adult Women WITH Special Needs

Catharine A. Kopac, PhD, GNP

Although I am a student of life-span development, my area of focus since the mid-seventies has been gerontology. Only in the last decade have I become aware that persons with developmental disabilities are such a vulnerable, diverse group. My realization came quite by chance, when a nurse midwife asked me to help her write a clinical article about teenage girls with developmental disabilities who need gynecological and reproductive (Gyn/Rep) care. I agreed to help her and in doing a review of the literature became aware of the paucity of research on this topic. I found that it was nearly impossible to obtain reliable information on the numbers of teens and adult women with special needs. Fortunately, a neighbor and exercise companion, Joni Fritz, was then the Executive Director of the American Network of Community Options and Resources. Her understanding of the field of developmental disabilities, born out of more than twenty years of organizational and advocacy experience, enabled me to frame research questions that could be used to survey the population. Our initial results led to further studies; now we are into our third wave of research on the topic. In this article, I will present an overview of what we learned in our first study and summarize recommendations that we would make to parents, caregivers and health care professionals who support teenagers and women with special needs.

> "Visits go pretty good. He shakes my hand."

In the beginning, my colleague and I had to define what we meant by developmental disabilities. The definition that we have used consistently in our research is: "Developmental disabilities are chronic disabilities affecting people before the age of 22, which are attributed to mental and/or physical impairments and expected to last life-long, and which result in numerous limitations of major life activities." This is a modification and abbreviation of the definition in the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 104-183), Title I, Part A, Section 102(8).

Our first study, using a mail-out questionnaire, was directed towards teenage and adult women with special needs and the agencies that serve them; 127 women with special needs and 155 professionals, representing a similar number of agencies, responded. It is important to remember that the data collected represent responses from a group of women with special needs and the agencies that voluntarily completed and returned questionnaires. We are very much aware that among vulnerable populations, those with the greatest need tend to be those who speak up the least or have "no voice." Nevertheless, the results clearly reveal issues that need attention.

> "Well I wouldn't have a Pap smear until we compromised. [Agency name] said what if we went to a female doctor and I said OK."

Barriers to care

A number of barriers prevented women in the study from receiving Gyn/Rep care. Very often the barrier was financial: difficulty in finding a provider who accepts Medicare and Medicaid; lack of health insurance for some women who work; and unavailability of adequate insurance coverage. One-fifth of the agencies reported having difficulty accessing Gyn/Rep services for the people they support. If the agencies are having problems, then women and/or their families who try to secure care by themselves must face even greater difficulties.

For the women as a whole, problems in securing care were related to comfort; there was no staff member present to assist the patient and help establish ease with the health care provider. In addition, more than 16 percent of the women said fear was an impediment to seeking care; the majority "did not like" the pelvic examination; and one third "did not like" mammograms. More than half the women said they preferred a female physician. The majority of the women did report that their own physician and/or nurse provided time for them and answered their questions. We asked the repondents to "tell us in a few words about these visits to the doctor or nurse;" their comments were very revealing (see them highlighted throughout this article).

Agencies also reported barriers created by family perceptions of sexuality of the teenage and adult women they supported. They ranged from the denial of the need for regular gynecological care to a perception that persons with special needs were "asexual" and had no need for information regarding management of sexual and reproductive health. To complicate matters, 11 percent of the agencies reported that the teenage and adult women they supported were uncooperative during examinations, and five agencies reported that some women had to be sedated prior to examinations. Nearly eight percent of the agencies reported that, even when reimbursement was not an issue, it was difficult to find professionals who were willing to provide services. Despite these problems, more than half the agencies reported that all the women they supported received some gynecologic services, generally the yearly pelvic examination.

> "My doctor's a woman and I relate to her…I feel like she's a friend and that I can talk to her about anything…she sets and listens without rushing."

The study results clearly demonstrated that the bulk of care-giving for and advice-giving about gynecologic concerns was provided by direct support staff or registered nurses. Other findings indicate that, in addition, the survey participants were likely to seek out a staff member or a registered nurse before consulting a physician. This suggests that staff support is key to accessing health care services for many teenage and adult women with special needs.

Services Provided

Only about a quarter of the responding agencies reported that health education was available to all of the teenage and adult women they supported; about half of these provided health education on-site. This percentage seems very low when one considers that these agencies exist to empower the people they serve and to assist them in becoming more self-dependent. It was significant that some of the women respondents expressed a desire to receive more health education.

> "I'm pleased that staff from my home [in Michigan] let me keep my doctor in Indiana. Staff transport me. Sometimes my sister."

A surprising finding was that so many agencies (55.4 percent) did not provide treatment and counseling for sexually transmitted diseases (STDs) and many agencies did not provide STD screening (40.6 percent). While some of the reporting agencies may have referred people to another agency for these services, this number is still alarmingly high; and no respondents reported that their agency referred women elsewhere for these services. Professionals in the field have long recognized that persons with special needs are often perceived as being asexual or sexually inactive. Such attitudes, when coupled with the challenge of providing health education to people whose developmental disabilities include mental retardation, pose unique challenges for the delivery of care. When the lack of STD services is combined with insufficient health education, one suspects that protection against the spread of human immunodeficiency virus (HIV) infections and other STDs may be highly inadequate.

While many of the women did not acknowledge the use of, or rate their satisfaction with, birth control, pregnancy care, STD screening or STD treatment, a significant correlation cluster did emerge. This cluster indicated that many of the women who were sexually active were likely to use services necessary for responsible sexual behavior.

Recommendations

This article has addressed a number of findings. The recommendations that flow from these findings are many. The major ones are summarized here:

◆ Monitor reimbursement strategies and rates for gynecological and reproductive care for teenage and adult women with special needs. Reimbursement for these services must be adequate. Reimbursement must be provided for "well-woman" care (Pap smears, mammograms, STD screening).

◆ Provide gynecological and reproductive care as a separate "arm" of services. Services should be clustered to facilitate easy access for persons with special needs. Appointments should be made at special times (beginning or end of day) to facilitate easy access to offices and allow adequate time for women with special needs. Office staff may need guidance on how to serve teenage and adult women with special needs.

◆ Recognize staff support as key to secur-

continued on page 56

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #18 or visit www.eparent.com/adinfo

continued from page 55

ing services for teenage and adult women. It is essential in reassuring patients, promoting individualized care and enabling primary care providers to deliver quality care.

◆ Recognize that comfort with the care provider is central to service delivery. Providers need education to gain an understanding of the nuances and skills needed to provide safe, quality care to this population.

◆ Acknowledge that health education is a major component of comprehensive, coordinated, safe gynecological and reproductive care. It must be directed to teenage and adult women with special needs, parents and caregivers. Tailored materials, classes and approaches are necessary.

◆ Offer STD screening, counseling and treatment to teenage and adult women with special needs. Education is essential for persons with special needs, their family members and their direct support professionals to understand prevention, detection and treatment of sexually transmitted diseases, and to reduce the potential for sexual abuse.

> "Previously, many ob-gyns reluctant to do exam—fearful I would have seizure during exam."

Conclusion

This study showed that the provision of gynecological and reproductive care for teenage and adult women with special needs has much room for improvement. As with most health care services that are delivered to vulnerable populations, there is a need for consumers and professionals to assume a vigilant, assertive posture to obtain and provide this care. It is the combined efforts of the teenage and adult women themselves, their families, support staff and health care providers in addressing the challenges of teenage and adult women with special needs that will be effective in improving the availability and accessibility of these services. **EP**

This material was excerpted from: Kopac, C, Fritz, J, Holt, R (1996). Availability and Accessibility of Gynecological and Reproductive Services for Women with Developmental Disabilities-Executive Summary. American Network of Community Options and Resources (ANCOR), Alexandria, VA.

Catharine A. Kopac is currently a primary care research fellow in the Center for Clinical Bioethics at Georgetown University Medical Center in Washington, D.C. At present, she has a research and practice interest in three vulnerable populations: persons with Alzheimer's disease, older adults requiring long-term care and women with developmental disabilities.

The Relationship Between Oral Health and Genetic Disorders, Part II

DEVELOPMENTAL ANOMALIES OF THE ORAL CAVITY

It is estimated that about 25% of Mendelian disorders have craniofacial manifestations. The great majority of chromosomal disorders and several environmental disorders affect the oral cavity. In this paper we will describe isolated, as well as associated, oral anomalies and/or traits.

ISOLATED ORAL ANOMALIES

Anomalies of Tooth Number

Missing Teeth This trait is known as hypodontia, the congenital absence of one or more teeth. The term anodontia should be reserved for the total absence of primary and secondary teeth, and modifications of anodontia (i.e., partial anodontia, pseudoanodontia) should not be used at all.

Hypodontia is a rather common characteristic of contemporary men; the incidence ranges from 2% to 6%, excluding third molars, and higher incidences have occasionally been reported. The incidence varies among populations. Family studies have shown absence of the upper lateral incisor is controlled by one autosomal dominant gene with high transmittal occurance and variable expression. It may occur unilaterally or bilaterally, and nine combinations of peg-shaped, absent, and normal incisors have been described.

Absence of the third molar is common and is thought to be controlled by polygenes. It has been reported as both autosomal dominant and autosomal recessive. Although the trait has been known for more than a century, no conclusive data are available. Certain patterns of missing teeth have lately been described as single gene disorders.

Supernumerary Teeth The presence of supernumerary teeth is known as hyperdontia, which is observed less frequently than hypodontia. In most cases, supernumerary teeth are not visible; roentgenograms are necessary to document the presence of impacted supernumerary teeth. Supernumerary teeth vary in morphology. Although they may have characteristics similar to normal teeth, a great number of them are abnormally shaped. Supernumerary teeth are common in the maxillary anterior area (mesiodens) and the maxillary molar area (distomolars or fourth molars). Some cases of supernumerary teeth have been shown to be compatible with genetic transmission.

Anomalies of Tooth Structure

Two main categories of defects affecting enamel and dentin have been described: defects caused by environmental factors during the development of teeth and defects caused by genetic factors.

Environmental Defects

Tetracycline Stain Drugs such as tetracycline are well known as agents that produce discoloration of the teeth. Generally, the color ranges from yellow to slightly brown or blue. The teeth affected are those that were mineralizing while the drug was used. Tetracycline is incorporated with calcium and may be observed in dentin or enamel, which are tooth structures. A clinical history of treatment with tetracycline and fluorescent teeth (yellow fluorescence) under ultraviolet light are criteria in making the diagnosis.

Fluorosis Fluoride ingested with drinking water may produce fluorosis, changes in the enamel. Fluorosis ranges from a few white flecks to brown stains. When fluorosis is severe, the surfaces of teeth appear eroded. The brown color results from hypoplastic enamel and is observed mainly in areas where the fluoride

continued on page 58

continued from page 57

concentration in drinking water is higher than 2 ppm.

Vitamin Deficiencies Nutritional deficiencies may also account for structural defects of teeth. Vitamin D deficiency causes rickets and dental changes that may be manifested as large pulp chambers with high pulp horns, enamel hypoplasia, and microexposures of pulp horns that result in abscesses. In vitamin A deficiency, although enamel hypoplasia is not seen clinically, there is histological alteration of enamel and dentin. Enamel hypoplasia has also been reported in vitamin D hypervitaminosis.

Trauma Trauma during tooth development may cause severe enamel hypoplasia or dilaceration of the teeth. Intrusion of the primary teeth into developing permanent teeth is a common cause of such defects.

Virus Infections in early pregnancy caused by viruses such as rubella may produce dental defects such as hypodontia and enamel hypoplasia of the primary teeth. However, the evidence is not conclusive.

Inherited Enamel Defects (amelogenesis imperfecta)

This group of well-established disorders has been divided into three main types: hypoplastic, hypocalcified, and hypomature. The criteria for classification are the clinical, roentgenographic, and histological features of the enamel.

Hypoplastic Amelogenesis Imperfecta Several types of hypoplastic amelogenesis imperfecta have been described. The enamel may be smooth, pitted, rough or locally rough (all autosomal dominant), or it may have alternating vertical bands of normal and abnormal enamel (X-linked dominant). Lack of interproximal contact because of lack of normal depth of the enamel layer is frequently observed in the smooth and rough types of hypoplastic amelogenesis imperfecta. The enamel may vary from yellowish to brownish, and generally both primary and permanent teeth are affected.

Hypocalcified Amelogenesis Imperfecta This is the most common type of amelogenesis imperfecta. The enamel may be stained by exogenous agents and tends to be brown or black. In hypocalcified amelogenesis imperfecta, the enamel surface is pitted and chips off, thereby exposing the dentin. The teeth are sensitive to changes in temperature. Roentgenographically, the enamel is of normal thickness but has a moth-eaten appearance. The mode of inheritance is autosomal dominant.

Hypomature Amelogenesis Imperfecta Several types of hypomature amelogenesis imperfecta have been described. Generally, discoloration of the enamel ranges from white to yellow-brown. A dental explorer may penetrate the surface of the enamel in the X-linked recessive type. In the autosomal recessive type, the enamel tends to chip away. Enamel cannot be distinguished from dentin on the roentgenogram.

Inherited Dentin Defects

Dentinogenesis Imperfecta Synonyms such as hereditary opalescent dentin have been used to describe opalescent brown teeth as a heritable, isolated defect.

An increasing number of oral anomalies of the hard and soft tissues are being recognized as associated with multiple-system disorders.

Dentinogenesis imperfecta is manifested as discoloration (brown to blue) of teeth that wear down easily just through chewing. The crowns of teeth, especially the bicuspids and molars, are bulbous in appearance, with a constriction at the junction of enamel and cementum. Roentgenographically, the bulbous appearance and constriction at the cervix are more evident, and obliteration of pulp chambers and the root canals can be seen. The roots have also been described as short. The roentgenographic findings mentioned are typical of dentinogenesis imperfecta and of opalescent dentin-enamel teeth associated with osteogenesis imperfecta.

In dentinogenesis imperfecta, the enamel chips off easily, apparently because of a lack of physical retention at the dentin-enamel junction. The exposed dentin is susceptible to attrition. In some cases the crowns of the teeth are worn away and opalescent brown roots with obliterated root canals are observed.

Preventive treatment should include steel crowns on primary molars to avoid attrition and loss of vertical dimension. In permanent teeth, full dentures over crowned teeth have been shown to be successful. Full crowns over teeth with dentinogenesis imperfecta have not been fully accepted because of fear of fractures at the level of the pronounced constriction, but cases have been reported in which such treatment is successful.

Dentin Dysplasia Other dentin anomalies include dentin dysplasia with its variants. Type I is recognized roentgenographically as agenesis of the roots, while pulp obliteration in primary teeth, thistle-tube pulp and numerous pulp stones in permanent teeth are characteristic of type II. Both defects are inherited as autosomal dominant traits, and teeth in both dentitions are affected.

Anomalies Of Bone

Torus Palatinus A hard bony structure generally located in the posterior midline of the hard palate is known as torus palatinus. This bony exostosis is a benign tumor that may show a domelike form or may be lobulated. Occasionally it is present as a spindle running anteroposteriorly at the midline of the palate. Generally it is observed in adults and adolescents, but personal observations have been made at earlier stages. Torus palatinus should be surgically removed in patients with speech impairment and when the patient is a candidate for upper dentures.

Torus Mandibularis An exostosis on the lingual surface of the mandible, generally near the site of the canines, is known as torus mandibularis. This exostosis may be single or multiple, is usually bilateral and, like the torus palatinus, is a benign tumor. Surgical excision is the treatment of choice if the torus interferes with speech or dentures. Torus mandibularis has been reported to be autosomal dominant.

ORAL ANOMALIES ASSOCIATED WITH GENETIC DISORDERS

An increasing number of oral anomalies of the hard and soft tissues are being recognized as associated with multiple-system disorders. In several cases, the oral findings represent manifestations of the syndrome: in other cases, the oral findings are coincidental. Several syndromes are described below in which the oral findings are a recognized manifestation of the syndrome.

Anomalies of Tooth Number Associated with Genetic Syndromes

Congenitally missing teeth and supernumerary teeth have been shown to be associated with several inherited syndromes. Congenitally missing teeth are seen in Witkop syndrome, Böök syndrome, hypohidrotic ectodermal dysplasia, incontinentia pigmenti, Ellis-van Creveld syndrome, Hallermann-Streiff syndrome, focal dermal hypoplasia, lipoid proteinosis, Rieger syndrome, otodental dysplasia, Coffin-Lowry syndrome, trichodental syndrome and others. Supernumerary teeth have been documented in cleiodocranial dysplasia and Gardner syndrome. A few of these will be discussed as examples of the nature of abnormal numbers of teeth in syndromes.

Hypohidrotic Ectodermal Dysplasia, X-Linked Recessive This is the most common type of ectodermal dysplasia; males are severely affected while females are carriers and very mildly affected. The disorder is characterized by sparse thin hair, multiple congenitally missing teeth, abnormal conically shaped teeth, lack of sweat pores and nail abnormalities. In these patients, both dentitions are affected; teeth, when present, are abnormal in shape and smaller in size. On occasion, patients may be completely edentulous. In regions where teeth are missing the alveolar ridges are poorly developed or even flat.

Dental treatment may require construction of dentures that are well tolerated, even for children at four years of age. Dental implants are an excellent alternative for older children and there are now several centers that utilize this procedure. A good resource of information is the National Foundation for Ectodermal Dysplasia (http://www.nfed.org).

Witkop Syndrome or Tooth and Nail Syndrome This syndrome is characterized by multiple congenitally missing teeth, conical deciduous and permanent teeth and dysplastic nails. At birth, nails are very small or nonexistent. Later, they may remain smaller than normal; some, particularly the thumbnail and the nail of the big toe, may have a flat or depressed center with the appearance of a spoon-shaped nail.

This condition will not affect the sweat pores or the hair, and it is an autosomal dominant trait. Because this condition is relatively benign, people are treated only for the correction of their teeth and little attention is given to the nail abnormalities.

Incontinentia Pigmenti This disorder is a genodermatosis characterized by a pigmentary change of the skin resulting in hyper-pigmented tattooing of the skin. In addition, people with the disorder may show a variety of malformations of the hair, eyes, teeth, skeleton, and central nervous system. They may also have developmental delays. Dystrophy of the nails occurs infrequently and is usually mild. Possible teeth abnormalities include congenitally missing teeth, conically shaped teeth, and small teeth (microdontia). Skin changes may disappear with age, and mothers of children with incontinentia pigmenti should be examined for orodental findings that may be the only clinical evidence that they have the disorder.

Incontinentia pigmenti is inherited as an X-linked dominant disorder and in males is usually lethal prenatally. A good source of information is the Incontinentia Pigmenti International Foundation at http://imgen.bcm.tmc.edu/IPIF.

Coffin-Lowry Syndrome This syndrome includes mental retardation, faciodigital anomalies, skeletal abnormalities and orodental abnormalities. The facies is characterized by progressive coarsening of the facial features, along with hypertelorism, antimongoloid slanting of the palpebral fissures, prominent supraorbital ridges, short and anteverted nares, open mouth (in males), pouty lower lip, thick bulging chin, and protuberant ears. It may be confused with that seen in the mucopolysaccharidoses, Williams syndrome, Down syndrome, or acromegaly in adolescents. Skeletal findings include marked scoliosis, pectus excavatum, hyperextensible hands and flat feet. The hands are pudgy, with distally tapering fingers. Orodental findings in Coffin-Lowry syndrome include malocclusion, midline furrow of the tongue and hypodontia. The syndrome is thought to be X-linked or sex-influenced autosomal dominant.

Rieger Syndrome Rieger syndrome is the autosomal dominant association of goniodysgenesis (abnormal development of the anterior chamber of the eye), congenitally missing teeth, and failure of involution of the periumbilical skin (prominent belly button). Goniodysgenesis in Rieger syndrome is manifested primarily as a prominent Schwalbe line, hypoplasia of the iris stroma, and iridocorneal synechiae. Glaucoma, cataract, and microcornea may be associated with the goniodysgenesis. The upper anterior teeth are those absent most frequently. The mandibular incisors are often conical in shape or absent and one or more of the premolars may be absent.

Cleidocranial Dysplasia Cleidocranial dysplasia is characterized by lack of normal development or absence of the clavicle bone, late ossification of cranial sutures, frontal and parietal bossing, shortness of stature and orodental abnormalities. The syndrome is autosomal dominant. Delayed eruption of teeth or lack of teeth have been described; the teeth are actually impacted, and their presence is revealed by radiographs. Supernumerary teeth are one of the most peculiar characteristics of the syndrome. Their shape is similar to that of bicuspids.

Tooth Morphology Alterations Associated with Genetic Syndromes

Otodental Dysplasia Otodental dysplasia is an ectodermal dysplasia characterized by sensorineural deafness and large,

continued on page 60

continued from page 59

bulbous teeth. The age of onset and progression of deafness vary. Some affected individuals may even reach middle adult life without a hearing impairment.

The crowns of molars in affected individuals are larger than average, bulbous, and lack normal cusp and sulcus occlusal patterns. The premolars are frequently smaller than average or absent altogether. In some families only the deciduous canines are affected, while in others both the deciduous and permanent canines are involved, becoming large and bulbous. Pulp stones may be seen on radiographs of affected teeth. The pulp chambers appear to be duplicated, and taurodontism (long pulp chambers and short roots) may be present. Otodental dysplasia is inherited as an autosomal dominant trait with high transmittal occurence and variable expression of the associated defects.

In males the enamel is hypoplastic and thin. The roots of affected teeth are generally more tapered than normal, and the apex remains open longer than usual.

Morquio Syndrome This syndrome is also called mucopolysaccharidosis IV. Its manifestations are platyspondylisis, corneal opacities, keratosulfate excretion in urine and characteristic dental abnormalities. The skeletal changes include progressive spinal deformity, short neck, pectus carinatum, and marked growth failure. In a study of 12 patients with the condition, the anterior teeth were noted to be widely spaced and flared. The posterior teeth were tapered and had pointed cusp tips. The enamel was normal in hardness, but some had pitted surfaces. The hard palate was broad and flat, and dental radiographs showed hypoplastic enamel. The dental findings are unique among genetic mucopolysaccharidoses and are a good adjunct for clinical diagnosis. The syndrome is autosomal recessive.

Ellis-van Creveld Syndrome This syndrome shows hypodontia and alteration of crown morphology. The morphology of the remaining teeth, especially the anterior teeth, is characterized by conically-shaped lateral incisors or cuspids and barrel-shaped central incisors. The lateral margins of lingual surfaces of these teeth appear enlarged, and a high and prominent cingulum is common. Other dental findings include neonatal teeth, serrated alveolar ridge, supernumerary frenula and pseudo cleft lip resulting from a hyperplastic midline frenum.

Taurodontism In taurodontism the pulp chambers are enlarged in an apical direction and the bifurcation or trifurcation point of the molars is also displaced toward the apex. As a result, the tooth has the shape of a block with small divergent roots. Because the crown is not affected, taurodontism is essentially a radiographic finding. There are several syndromes associated with this unusual trait; this clinical sign may be helpful in the characterization of a given disorder. Syndromes with taurodontism include:

- Klinefelter syndrome, or 47 XXY, and also in individuals with an extra X chromosome such as XXXY or in those with XY:XXYY mosaicism;
- Trichodento-osseous syndrome;
- Mohr syndrome, or orofaciadigital syndrome type II;
- Hajdu-Cheney syndrome;
- Taurodontism, microdontia, dens invaginatus;
- Stoy syndrome (taurodontism, hypodontia, sparse hair);
- Ackerman syndrome (taurodontism, pyramidal and fused molar roots, juvenile glaucoma, unusual morphology of the upper lip).

Anomalies of Tooth Structure Associated with Genetic Syndromes

Trichodento-Osseous Syndrome The trichodento-osseous syndrome is potentially another ectodermal dysplasia, but the reported increase in bone density may remove it from the strict definition of ectodermal dysplasia. It is an autosomal dominant syndrome of excessively curly hair, enamel dysplasia, and radiodense bones. Affected individuals have tightly curled hair at birth; the hair may remain curly throughout life or may become straighter with age. The teeth are affected by enamel dysplasia that has been reported to involve hypoplasia, hypocalcification and, less commonly, hypomaturation. Other dental findings include increased dental caries and delayed dental eruption. Individual teeth can be affected by more than one type of dysplasia, most commonly a combination of hypoplasia and hypocalcification. Taurodontism is present in the trichodento-osseus syndrome, as is a higher-than-expected occurrence of impacted teeth. The cortices of bones appear excessively dense but normal in thickness on roentgenograms. Some affected individuals may have brittle nails that split longitudinally, but no other defects are consistently associated with the syndrome.

Osteogenesis Imperfecta This disease is characterized by bone fragility, blue scleras, hearing abnormalities and dental abnormalities. These last are clinically similar to those observed in dentinogenesis imperfecta: opalescent teeth with bulbous crowns and obliterated pulp chambers and root canals. A history of bone fragility and hearing impairment helps to differentiate dentinogenesis imperfecta from osteogenesis imperfecta.

A classification of osteogenesis imperfecta has been proposed on the basis of the dental findings associated with osteogenesis imperfecta tarda. This classification includes at least two autosomal dominant types, one in which the teeth are opalescent and one in which the teeth are normal. Because opalescent teeth may be evident at the eruption of first lower central incisors at approximately 6 months of age, the dental signs often precede bone fractures in cases of so-called osteogenesis imperfecta tarda.

Pseudohypoparathyroidism There are two types of pseudohypoparathyroidism; they show similar enamel defects. Both are X-linked traits. The enamel defects vary according to sex, the stage of tooth development, and onset of the biochemical changes associated with pseudohypoparathyroidism. In females the enamel [illegible] teeth is markedly pitted. In males the enamel is hypoplastic and thin. The roots of affected teeth are generally more tapered than normal, and the apex remains open longer than usual. The disorder results from an abnormal response to parathyroid hormone; although the hormone is normal in amount, both hypocalcemia and hyperphosphatemia occur.

Anomalies of the Jaw Associated with Genetic Syndromes

Pyknodysostosis This syndrome is characterized by small stature, bone abnormalities, persistence of the fontanelles, large head with occipital prominence, prominent nose, short fingers caused by hypoplasia of the distal phalanges, and absence of the angle of the mandible. Absence of the angle of the mandible is a constant feature that is virtually pathognomonic. Other dental abnormalities include premature eruption of the teeth and hypodontia. Pyknodysostosis is inherited as an autosomal recessive trait.

Cherubism Cherubism is characterized by symmetric bilateral enlargement of the mandible. The condition may begin as early as 2 years of age. The lesion is hard to the touch, and painless. In some instances, cherubism may affect the maxilla, with involvement of the floor of the orbit. This complication displaces the globe upward and exposes the scleral rims, suggesting a cherubic look. A summary of a report on a 4-year-old male of apparently triracial extraction can be illustrative. There was no history of consanguinity or of a similar condition in his family. The child, who was referred to us with a diagnosis of Noonan syndrome, was short in stature and had a congenital heart defect, bilateral palpebral ptosis, and bilateral enlargement of the mandible in the area of the first and second molars. Roentgenograms revealed characteristic multiloculated radiolucencies in the area of the molars that extended almost to the lower border of the mandible. Several teeth were displaced by lesions.

The natural history of cherubism shows that the lesions of the maxilla and mandible eventually regress. The regression may be noticed during puberty, yet later in life no sequelae of the condition are found. The man described above was monitored into adulthood. Although he has virtually no facial deformation now, he has very poor dentition because of caries and tooth displacement because of bone deformation. Furthermore, the alveolar ridge has a decreased height. In this particular case we found lesions on the ribs that were radiologically and cytologically similar to the lesions of the mandible. Cherubism is autosomal dominant, and many cases display new mutations.

Some oro-dental findings, such as congenitally missing teeth, amelogenesis imperfecta or cleft of the lip and palate, may be isolated defects.

Gardner Syndrome Gardner syndrome is characterized by a triad of alterations that include multiple osteomas, soft tissue lesions such as epidermoid cysts and fibromas of the skin, and multiple polyposis of the large intestines. The most common sites for osteomas in this syndrome are the frontal bone, maxilla, mandibular angle, and lower border of the mandible. Other oro-dental findings include multiple odontomas, supernumerary teeth, and impacted teeth.

Recognition of the osteomas is important because they generally precede the appearance of intestinal polyposis, which has a marked tendency towards malignant degeneration. By 30 years of age about 50% of cases are of malignant degeneration, and the percentage increases with age. Potential colon cancer may warrant prophylactic colon removal in early adult life.

SUMMARY

In this article and Part I (December 2001 issue), we have illustrated the relationship between oral-dental findings and genetic disorders. Some oro-dental findings, such as congenitally missing teeth, amelogenesis imperfecta or cleft of the lip and palate, may be isolated defects. However, there is ample evidence of oral-dental findings that are found as part of a more complex systemic disorder. The clinical relevance of the findings varies; they may only be descriptive, such as a fissured tongue in Down syndrome, but in other cases missing teeth may represent an important finding in the diagnosis of ectodermal dysplasia, X-linked recessive, incontinentia pigmenti or Rieger syndrome. Brownish or opalescent baby teeth may be the first sign of osteogenesis imperfecta, while freckle-like spots on the lips may indicate intestinal polyposis, as in Peutz Jeghers syndrome.

We would like to emphasize that children with special health care needs should be examined by a dentist by the time they are one year old. This will allow the dentist to advise the parents about nutritional aspects, oral hygiene habits, and preventive measures. Furthermore, the dentist will play an important role in the integral approach regarding health care needs of the child, in collaboration with the physician and the parents. Good dental health goes far beyond having good teeth. Let us work together to bring a bright smile to our special children!

Dr. Carlos F. Salinas is Professor and Director of the Division of Craniofacial Genetics, Department of Pediatric Dentistry and Orthodontics, College of Dental Medicine at the Medical University of South Carolina, Charleston, SC.

WWW.EPLIBRARY.COM

EP Exceptional Parent LIBRARY

THE SPECIAL NEEDS BOOKSTORE

FOR YOUNG PEOPLE

How Many Days Until Tomorrow?
J. Caroline Janover
Josh, a 12 year old with dyslexia, is spending the summer with his older brother and grandparents on a remote Maine island. This is the story of how he finds adventure and discovers new talents in the sometimes rugged wilderness of Maine.
WB7224FY $11.95

Mama and Daddy Bear's Divorce
Cornelia Maude Apelman ACSW, LCSW
To a young child, divorce need be explained only in the simplest terms. This book emphasizes the precious things in a child's life that stay the same. The message conveyed is that no matter where the parents live, they will always love their child.
AWL2IGN $14.95

Nursery Rhymes from Mother Goose
Told in Signed English
Harry Bornstein and Karen L. Saulnier; Illustrated by Patricia Peters and Linda Tom
More than a dozen favorite rhymes illustrated with full color paintings accompanied by 389 drawings showing verses in Signed English. Designed to help young readers strengthen their language skills
GU108TP $14.95

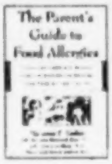
EPILEPSY

Epilepsy: The Facts
Second Edition
Anthony Hopkins and Richard Appleton
This excellent book is designed to present the facts about every aspect of epilepsy in a clear and concise manner. Written by a neurologist, it presents a clear definition of epilepsy, the different types of seizures associated with the disorder, the medical and surgical therapies used, as well as providing practical points on living with epilepsy.
OU5489EP $19.95

Brain Development and Epilepsy
Philip A. Schwartzkroin, Solomon L. Mosh, et al.
This integrated volume applies the emerging concepts in neurobiology to develop an understanding of the origins of the epilepsies of childhood. This practical text covers age specific epilepsies, experimental approaches and therapies, and the integration of such knowledge to help formulate a plan to assist in effective treatment for these often devastating syndromes.
OU8462EP $59.95

Lee, The Rabbit With Epilepsy
Deborah M. Moss
A reassuring tale for young children with epilepsy. The story follows Lee from her first seizure to the doctor's office, and then home with new medication to control her seizure. Ages 4-8
WB182EP $12.95

GENERAL



The Parent's Guide to Food Allergies
Clear and Complete Advice From the Experts On Raising Your Food- Allergic Child
Marianne S. Barber with Maryanne Bartoszek Scott M.D. and Elinor Greenberg, Ph.D.
Whether you are the parent, relative, caregiver, or teacher of a food-allergic child, you know how challenging it is to keep that child safe, healthy, happy, and well fed. The team of authors behind this invaluable book—the mother of a food-allergic child, a board-certified allergist, and a psychologist—will take you through every step of life with a food allergic child. Included issues are: allergy testing-what you need to know; diagnosing and treating anaphylaxis; in-depth discussion of top eight most common food allergies; recipes that are easy, delicious and kid friendly plus much more.
WH5004FA $15.00

The New Language of Toys
Teaching Communication Skills to Children with Special Needs
S. Schwartz, Ph.D. & J.E. Heller Miller, M.Ed.
An updated and expanded how-to guide for using everyday toys to develop communication skills in children with disabilities and make playtime a fun, exciting, and educational experience.
WB1590D $16.95

The Read Aloud Handbook
Jim Trelease
This book makes reading aloud a special pleasure for millions of people. It offers a chance for a new generation of parents, teachers, grandparents, and siblings to discover the rewards and the necessity of reading aloud to children. Not only does the book emphasize the importance of reading aloud, but it also provides valuable time for parents and teachers to spend together with children.
GP9710GN $13.95

DOWN SYNDROME

Gross Motor Skills in Children with Down Syndrome
A Guide for Parents and Professionals
Patricia C. Winders, P.T.
A how-to guide for meeting the challenges Down syndrome presents for gross motor development, coordination of large muscle groups and the sequencing of movements in young children. This book provides guidance for parents of children ages birth through 6 years.
WB171DS $16.95

Babies with Down Syndrome
A New Parents' Guide
Second Edition
Edited by K. Stray-Gundersen
A newly revised complete
and compassionate guide,
written by doctors, nurses, educators, lawyers, and parents.
WB156DS-ENGLISH $15.95
WB178DS-SPANISH $15.95

EARLY INTERVENTION

Early Intervention/Early Childhood Special Education
Recommended Practices
Samuel L. Odom and Mary E. McLean
An elaborate, yet easy to understand, description and supports of the practices that deal with early intervention. Both specific and general practices are discussed by leaders in the field.
PE125EI $39.00

An Activity Based Approach To Early Intervention
Diane Bricker, Kristie Pretti-Frontczak, and Natalya McComas
An ideal text for anyone involved in the fields of early intervention, special education, and child development. It serves as a practical guide in service resources for program administrators, therapists, interventionist, and other members of transdisciplinary teams.
PB3513EI $35.00

GRIEVING

Remembering With Love
Messages of Hope for the First Year of Grieving and Beyond
Elizabeth Levang, PhD. and Sherokee Ilse
An affirming gift for those grieving the loss of a loved one, offering compassion, comfort and guidance with over three hundred short pieces written by those who have been through the greiving process.
FP040DE $11.95

What on Earth Do You Do When Someone Dies
Trevor Romain
A down to earth explanation for children about death. It offers many ways for children to cope with and understand what happens when someone dies.
FS400DE $7.95

Guiding Your Child Through Grief
Mary Ann Enswiler, MA, MRS, and James P. Enswiler, MA, M.Ed
This caring and compassionate guide offers expert advice during the difficult days to help a child grieve the death of a parent or sibling. This book helps readers understand the many secret ways children grieve and offers more insightful information, and advice that can help a child heal.
BO0257GR $13.95

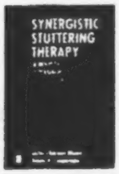
COMMUNICATION

Communication Based Intervention for Problem Behavior
A User's Guide for Producing Positive Change
Edward G. Carr; Len Levin; Gene McConnachie; Jane I Carlson; Duane C. Kemp and Christopher E. Smith
Consolidating years of important research and personal skill, this step by step guide details innovative methods for managing episodes of problem behavior, conducting initial ongoing functional assessments, selecting and teaching forms of communication, and working toward maintenance and generalization. This is an indispensable resource to help individuals with disabilities curtail problem behavior and gain greater independence in the community.
PB1596GN $29.95

YOUR CHILD'S SPEECH AND LANGUAGE **NEW!**
Guidelines for Parents
MARY BROOKS,
DEEDRA ENGMANN-HARTUNG

This charmingly illustrated 52-page book provides information for parents and others who want to know what to expect in the way of speech and language development from infancy through 5 years, and what parents and others can do to help develop normal speech and language.

PB132CM $14.00



SYNERGISTIC STUTTERING THERAPY
A Holistic Approach
SR. CHARLEEN BLOOM AND
DONNA K. COOPERMAN, PH.D.

Learn the details of a program that integrates the principles of speech production with the socioemotional aspects of communication. Discover how to structure individual treatment plans based on attitude, behavior, and interaction within their environment.

BH110CM $40.00

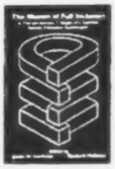
INCLUSION

QUICK GUIDES TO INCLUSION

QUICK GUIDES TO INCLUSION
Ideas for Educating Students with Disabilities
MICHAEL F. GIANGRECO

With brief factual summaries and to the point suggestions, the book is easy to use and focused on the topics most essential to successful inclusion. An entry level guidebook for new teachers and a concise summary of practices for seasoned professionals.

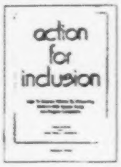
PB143ED $22.95



THE ILLUSION OF FULL INCLUSION
A Comprehensive Critique of a Current Special
JAMES M. KAUFFMAN AND
DANIEL P. HALLAHAN

A collection of analyses by nationally recognized individuals who raise serious questions about the full inclusion of all students with disabilities into general education.

PE178IN $31.00

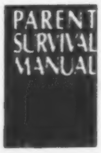


ACTION FOR INCLUSION
How to Improve Schools By Welcoming Children with Special Needs Into Regular Classrooms
O'BRIEN AND FOREST WITH SNOW,
PEARPOINT, AND HASBURY

An extraordinary plain language guide to inclusion. Provides a clear presentation of the values behind full inclusion and outlines a sensible series of actions that can be followed to make full inclusion a reality.

IP700ED $15.00

AUTISM



PARENT SURVIVAL MANUAL
A Guide to Crisis Resolution in Autism and Related Developmental Disorders
EDITED BY E. SCHOPLER

Includes many practical suggestions for dealing with the day-to-day challenges of life with a child who has autism.

PL14900 $39.50

PRESCHOOL EDUCATION PROGRAMS FOR CHILDREN WITH AUTISM
SANDRA L. HARRIS AND JAN S. HANDLEMAN

An especially helpful text for those who are considering creating a classroom to serve these children. It is also a checklist to ensure that the services currently offered are state of the art.

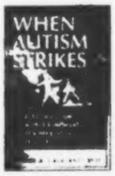
PE145ED $33.00

AUTISM THROUGH THE LIFESPAN

AUTISM THROUGH THE LIFESPAN
The Eden Model
DAVID L. HOLMES, ED.D.

A unique and detailed look at a successful approach to treating and caring for children with autism. Parents, teachers, and treatment professionals will find this book to be informative and insightful reading.

WB176AT $21.95



WHEN AUTISM STRIKES
Families Cope with Childhood Disintegrative Disorder
ROBERT A. CATALANO, M.D

Eight stories of families coping with Autism, or Childhood Disintegrative Disorder offered by parents who wish to lend support and encouragement to others in similar circumstances, as they also cope with daily living while searching for solutions.

PL15100 $19.95

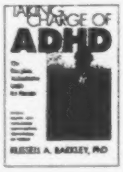
ATTENTION DEFICIT

Unlocking Potential

UNLOCKING POTENTIAL
College and Other Choices for People with LD and AD/HD
JULIANA M. TAYMANS, PHD,
LYNDA L. WEST, PHD, AND
MADELINE SULLIVAN, M.A.

This book is an indispensible tool for high school students with learning disabilities who are preparing for life after graduation. Filled with the latest information, advice, as well as practical tips and resources, this book is designed to make the transition from high school a success.

WB9948AD $18.95



TAKING CHARGE OF ADHD
The Complete, Authoritative Guide for Parents
RUSSELL A. BARKLEY, PH.D.

Pioneering research providing new insight into preventing ADHD from becoming a major obstacle in a child's and parent's life. Step-by-step ways to manage a child in everyday situations. Latest information on medications enhancing school performance and more.

GL030AD $17.95

Distant Drums, Different Drummers

DISTANT DRUMS, DIFFERENT DRUMMERS
A guide for young people with ADHD
BARBARA D. INGERSOLL, PH. D.

A view that offers children and adolescents struggling with ADHD the opportunity to see themselves in a positive light due to their penchant for novelty and exploration and boundless energy.

CP100AD $15.95

Beyond Ritalin

BEYOND RITALIN
STEPHEN W. GARBER, PH.D.,
MARIANNE DANIELS GARBER, PH.D.,
ROBYN FREEDMAN SPIZMAN

Facts about medication and other strategies for helping children, adolescents, and adults with ADHD.

NC100AD $13.50

SPINA BIFIDA

CHILDREN WITH SPINA BIFIDA

CHILDREN WITH SPINA BIFIDA
A Parent's Guide
MARLENE LUTKENHOFF, R.N., M.S.N.

A compassionate easy to understand volume that provides parents with information, guidance, and support to help meet their child's needs from birth through childhood.

WB201SB $16.95

AN INTRODUCTION TO SPINA BIFIDA

AN INTRODUCTION TO SPINA BIFIDA
DAVID G. MCLONE, M.D., PH.D.
AND JOY ITO, R.N.

The purpose of this book is to aid the parents, family and non-medical people who care for the child born with spina bifida. Revised 1998

SB095SB $6.00

ANSWERING YOUR QUESTIONS ABOUT SPINA BIFIDA
A Guide from the Spina Bifida Program Department of General Pediatrics
EDITED BY C. SHAER

Contains information to help understand basic medical, educational, and social issues of children and adults with spina bifida.

CN152SB-ENGLISH $6.95
CN153SB-SPANISH $6.95

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: **EP**, Dept. EP0202, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call **800•535•1910**

QTY.	ITEM#	UNIT PRICE	TOTAL
		Sub-Total	
		NJ Residents 6% Sales Tax	
		Shipping	
		TOTAL	

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

These prices are subject to change without notice.

Name ____________________
Address ____________________
City ____________________ State __________ Zip __________
Telephone ____________________ E-Mail ____________________
I have enclosed my check payable to EXCEPTIONAL PARENT or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover
Account Number: ____-____-____-____ Exp. Date ____/____
Signature ____________________

Circle #200

LEGISLATIVE UPDATE

IDEA Reauthorization Update– Input is Welcome

The Office of Special Education and Rehabilitative Services (OSERS) posted a Notice of Request on the Federal Register on January 10, 2002; it asks for public input by February 28, 2002, on the reauthorization of the Individuals with Disabilities Education Act (IDEA). All comments concerning the reauthorization of IDEA should be addressed to Thomas Irvin, OSERS. They can be e-mailed to: Comments@ed.gov. Please include "IDEA Reauthorization" in the subject line. They can also be mailed to: OSERS, 400 Maryland Ave. SW, Room 3086, Mary E. Switzer Building, Washington, DC, 20202-2570. For further information contact: JoLeta Reynolds or Thomas Irvin at: (202) 205-5507; (202) 205-5465 (TDD).

Employment and Training Grant Awarded to Serve Individuals with Disabilities

The Dept. of Labor's Employment and Training Administration awarded approximately $6 million in competitive grant funds for multi-site employment and training projects serving people with disabilities. The program targets projects that result in long-term, unsubsidized employment for people with disabilities.

Grants range between $300,000 and $500,000 for the first year, with a possibility of two additional years of funding. For more information, please visit: http://www.disAbility.gov.

Rare Diseases Act of 2001

The Rare Diseases Act of 2001 was placed on the Senate calendar on December 28, 2001. After its introduction on August 3, 2001 by Senators Edward Kennedy (D-MA) and Orrin Hatch (R-UT), the bill moved through the Senate Health, Education, Labor and Pensions (HELP) Committee quickly. It was approved in mid-October of 2001 and on December 18, 2001 it was passed as amended (S. 1379 RS) by a unanimous voice vote of the HELP committee. Kennedy and Hatch intend to bring the bill to the Senate floor for a vote as soon as possible.

The legislation is intended to further aid the estimated community of 25 million Americans who have a rare disorder. It was introduced along with S. 1341, an act to provide Orphan Drug tax credits that is currently under review in the Senate Finance Committee. S. 1379 is a third wave of the advocacy and reform that began with the 1983 Orphan Drug Act (ODA). The ODA provided 7 years of market exclusivity and expanded tax credits for companies developing and marketing orphan drugs, established an Office of Orphan Product Development at the Food and Drug Administration (FDA), and created the Orphan Products Grant Program. Before its passage, fewer than 10 orphan drugs had been developed between 1973 and 1983. Since passage of the Act, more than 220 new orphan drugs have been approved and more than 800 are currently under development. Since 1983 the ODA has been amended to clarify language and terms, improve efficiency of implementation and, most notably, convene a National Commission on Orphan Diseases to assess activities of public and private agencies.

In 1993, the Office of Rare Diseases (ORD) was formalized under the Office of the Director at the National Institutes of Health (NIH), following the recommendations of the Commission, Congress and patient advocates. In 1995, Senator Mark Hatfield (R-OR) recognized the need to enhance ORD's operations and introduced the Office of Rare Diseases Research Act, a bill that would have formally established the office at NIH. Though the bill passed the Senate, it was not enacted into law.

Without statutory authorization the ORD is often overlooked by the biomedical research community. S. 1379 will fortify the ORD by making it a permanent office at NIH; giving it statutory authority which will allow it to form its own research agenda; doubling its budget to $4 million in Fiscal Year 2002 and "such sums as may be necessary" for each subsequent fiscal year; authorizing new funds for Rare Disease Research Centers of Excellence in the amount of $20 million; and doubling the funding of the Orphan Product Research Grant Program at the FDA–which receives 100 grant applications yearly–to $25 million in FY 2002. The Congressional Budget Office estimates the five-year cost of the Rare Diseases Act to exceed $190 million, but has not quantified improvement in productivity or quality of life from effective drug therapy.

FOR MORE INFORMATION, VISIT:

- **Library of Congress Web site: http://www.thomas.loc.gov**
- **NORD Web site: http://rarediseases.org**
- **Capitol Switchboard: (202) 224-3121, (202) 225-1904 TTY**
- **Senate Web site: http://www.senate.gov**
- **House Web site: http://www.house.gov**

EDITOR'S NOTE:

EP Magazine strongly supports passage of the Rare Diseases Act of 2001. It broadens visibility for the Office of Rare Diseases at the National Institutes of Health and provides funding for research on rare disorders, orphan drugs and other treatments. We urge you to get behind this measure and tell your Senators and your Congressperson why the Act is so important to you and your family (see contact information above). Encourage your family and friends, the professionals who care for your family member with a disability, your colleagues, members of support groups–everyone you know–to speak out.

Approval of Pediatric Exclusivity Bill

On October 18, 2001, the Senate approved by voice vote a bill expanding the 1997 FDA Modernization Act's pediatric exclusivity rule, which was set to expire at the end of 2001. Senators Christopher Dodd (D-CT) and Mike DeWine (R-OH) co-sponsored the Best Pharmaceuticals for Children Act (S. 838); it will grant drug companies conducting clinical research on a drug's efficacy in children a six-month patent extension on that drug. The bill also expands the law to include newborns, establishes an Office of Pediatric Therapeutics at the FDA and sets up a "privately funded foundation" to research other drugs that are commonly used by children. "Kids are not just miniature adults. You can't just cut a pill in half," remarked DeWine (Billings Gazette, 10/19/01). The House passed its version (H.R. 2887) on October 11, by a vote of 41–6.

Bush Announces More than $76 Million for Homeless People with Disabilities

President Bush and Dept. of Housing and Urban Development (HUD) Secretary Mel Martinez have announced more than $1 billion in grants to help provide housing and support services to hundreds of thousands of homeless families and individuals across America. The announcement represents the largest amount of homeless assistance in history. More than $76 million of the grants awarded will go to the renewal of existing Shelter Plus Care projects which help pay rent and provide permanent housing for homeless individuals with disabilities.

National Housing Trust Fund

The Consortium for Citizens with Disabilities and other tenant advocacy groups saw a victory in June of 2001, when Representatives Bernie Sanders (I-VT), John McHugh (R-NY) and Barbara Lee (D-CA) introduced a bill (H.R. 2349) to create a permanent national housing fund. It was referred to the Subcommittee on Housing and Community Affairs on July 20, 2001. If established, this trust fund would create the first permanent trust fund for public housing dedicated to building and preserving rental housing for people with very low incomes, including people with disabilities. The senate version (S. 1248) was introduced by John Kerry (D-MA) on July 25, 2001, and was referred to the committee on Banking, Housing and Urban Affairs. For more information about the bill, or to contact a member of the Senate or the House, visit: http://www.senate.gov or http://www.house.gov

Rethinking Special Education for a New Century

Those who have an interest in special education and its current status in US legislative policy can download a free PDF version of "Rethinking Special Education for a New Century," which is located on the Web site: http://www.edexcellence.net. You can also order a free copy by calling (888) 823-7474. This 14-chapter volume scrutinizes the education now being received by 6 million children with disabilities in the US, and it is published with the participation of the Progressive Policy Institute.

President's Commission on Excellence in Special Education

The Commission on Excellence in Special Education was sworn in on January 15 and set out its agenda for the next four months. President Bush created the commission in October to collect information related to federal, state and local special education programs and to recommend policies for improving the education of students with disabilities. The commission is also charged with producing a final report to the president by this summer that contains findings and recommendations in the nine areas: Cost-effectiveness, Improving Results, Research, Early Intervention, Funding Formulae, Teacher Quality and Student Accountability, Regulations and Red Tape, What Models Work in the States, Federal v. Local Funding. For more information, visit the commission's Web site: http://www.ed.gov/inits/commissionsboards/whspecialeducation/index.html. EP

PEACE OF MIND

When it comes to your child, you don't compromise. Safety is indispensable. You demand quality. Reliability. Functionality.

The Lisa pediatric postural mobility system from Otto Bock gives you all this while maintaining its playful good looks. So go ahead. Take it "off sidewalk". Recline the back rest up to 130°. Accessorize to your heart's content. And enjoy how easily it folds and how little it weighs. You and your family deserve it.

For more information, visit www.ottobockus.com, or call 1-800-328-4058 to find a dealer near you.

Otto Bock
HEALTH CARE

Circle #43 or visit www.eparent.com/adinfo

Getting information from EP advertisers is MUCH FASTER ONLINE!

It's as easy as a click of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers

CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in EXCEPTIONAL PARENT.

How to use this service

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers
2. Circle the numbers'on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
16	ABILITIES EXPO	4
20	ADAPTIVEMALL.COM	80
18	ANNANDALE VILLAGE	56
21	BODYPOINT DESIGNS, INC.	14
22	COLUMBIA MEDICAL	9
23	CROTCHED MOUNTAIN REHAB	74
24	CYBERONICS, INC.	20-21
	CYCLETOTE CORP.	37
25	DURALIFE, INC.	12
26	EDEN FOODS, INC.	C3
200	EP LIBRARY	62-62
34	EP NEWBORN SCREENING DVD	52-53
199	EP SUBSCRIPTION CARD	17-18
27	EQUIPMENT SHOP	48
28	EVERGREEN CENTER	80
29	FREEDOM MOTORS USA	47
30	GLOBAL POWER SYSTEMS INC.	79
31	H.D.I.S.	42
32	HARD MANUFACTURING	16
19	HEARTSPRING	43
33	HMS SCHOOL	81
35	INNOVATIVE PRODUCTS	13
36	KIMBERLY CLARK CORP.	3
37	LAWYERS, INC.	25
38	LITIGATORS, INC.	15
39	M.J. MARKELL SHOE COMPANY	70
40	MELMARK	48
41	NEW JERSEY STORM	39
42	OCEAN HYPERBARIC CENTER	77
43	OTTO BOCK	65
44	REAL DESIGN	78
45	RED BARN ENTERPRISES	36
46	ROSS LABORATORIES–PEDIASURE	11
47	SAMMONS-PRESTON	7
48	SIGMA TAU	1-2
49	SNUG SEAT INC	C2
50	SOUTH FLORIDA CNTR FOR HOPE	70
51	STEWART HOME SCHOOL	12
52	SURE HANDS INTERNATIONAL	48
53	THE BABY JOGGER COMPANY	47
54	THE NYU HOSP FOR JOINT DIS CTR	8
55	TORONTO HYPERBARIC INC.	73
56	VAIL PRODUCTS	C4
57	VERIZON	23
58	WOODBURY PRODUCTS	13
59	WORLD CONGRESS	28-31

SUBSCRIPTIONS
EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-634-6550

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

EP
has the
information an
"Exceptional
Parent"
like you
needs

EP
Exceptional
Parent

Subscribe

on our

website:

www.eparent.com

and save

$5.00

For telephone

orders

call:

877-372-7368

To start your subscription to EP today, fill out the card near the front of this magazine or log on to

www.eparent.com

EXCEPTIONAL PARENT Free product & service information order card* **FEBRUARY 2002**

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______________________________

Address ______________________________

City ______________ State ______ Zip ______

Phone ______________ Fax ______________

E-mail: ______________________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? 1-☐ Yes 2-☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3-☐ Yes 4-☐ No

If Yes, are you a: 5-☐ Physician 6-☐ RN 7-☐ Physical Therapist
8-☐ Occupational Therapist 9-☐ Speech Pathologist; Audiologist
10-☐ Other (please indicate) ______________

D. Are you an EDUCATOR? 11-☐ Yes 12-☐ No

If Yes, are you a: 13-☐ Other (please indicate) ______________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? 14-☐ Yes 15-☐ No

If yes, please explain ______________________________

F. Do you use EP to find a product or service? 16-☐ Yes 17-☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

*CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: AUGUST 31, 2002

BFEB2

EXCEPTIONAL PARENT Free product & service information order card* **FEBRUARY 2002**

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______________________________

Address ______________________________

City ______________ State ______ Zip ______

Phone ______________ Fax ______________

E-mail: ______________________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? 1-☐ Yes 2-☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3-☐ Yes 4-☐ No

If Yes, are you a: 5-☐ Physician 6-☐ RN 7-☐ Physical Therapist
8-☐ Occupational Therapist 9-☐ Speech Pathologist; Audiologist
10-☐ Other (please indicate) ______________

D. Are you an EDUCATOR? 11-☐ Yes 12-☐ No

If Yes, are you a: 13-☐ Other (please indicate) ______________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? 14-☐ Yes 15-☐ No

If yes, please explain ______________________________

F. Do you use EP to find a product or service? 16-☐ Yes 17-☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

*CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: AUGUST 31, 2002

BFEB2

To start your subscription to EP today, fill out the card near the front of this magazine or log on to

www.eparent.com

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

No Postage
Necessary
if Mailed
in the
United States

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

No Postage
Necessary
if Mailed
in the
United States

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer life for themselves and for their children.

Exceptional Parent's MISSION

IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

SEARCH AND RESPOND INDEX 2001

EXCEPTIONAL PARENT'S "Search and Respond" column affords parents, caregivers, and professionals the opportunity to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. We try to print as many Search and Respond letters as possible in each issue and on our Web site: **http://www.eparent.com**. You can write, fax, or e-mail your letters to: EXCEPTIONAL PARENT Magazine, 65 East Route 4, River Edge, NJ 07661; fax: (201) 489-4111; e-mail: epedit@aol.com; or visit http://www.eparent.com on the Web and click on "Search and Respond," which is located on the homepage. It is important to indicate whether the letter is a "Search" or a "Respond." When sending a "Respond," please indicate the title, initials, month, and year of the "Search" letter you are answering. All "Responds" are forwarded to the writers of the "Search" letters, and most are published. For spacing purposes, all letters may be edited. (As with all matters concerning medical care and advice, individuals are also expected to consult the appropriate professionals regarding care.)

Following is an index of "Searches" and "Responds" from 2001. "Responds" are shown beside the "Searches" to which they refer.

Topic	Search	Respond
From Inclusion to Specialized School	Feb 01	Apr 01
Extreme Shyness	Feb 01	Mar 01
Limb Lengthening	Nov 00	Feb 01
Vacation	Nov 00	Feb 01
Custom Home Plans	Mar 01	
Tennis Shoes without Laces	Mar 01	May 01
Traveling Overseas	Mar 01	May 01
Ataxia	Nov 00	Mar 01
Dementia in a Child with Down Syndrome	Apr 01	
Ideas for Toys	Apr 01	Jul 01
Adapted Drinking Cup	Apr 01	
Adapted High Chair	Dec 00	Apr 01
Path for Wheelchair	May 01	
Looking for Pen Pal	May 01	
Menstruation Problems	May 01	Jul 01
Crying Spells	Jun 01	Oct 01
Inappropriate Behavior	Jun 01	Aug 01
Daughter Frustrated by Disability	Jun 01	Aug 01
Curvature of the Spine Worse After Surgery	Jun 01	
Child No Longer Drinking	Oct 00	Jun 01
Frequent Kneecap Dislocation	Jul 01	Sep 01
Son Chewing Shirts	Jul 01	Sep 01
Concerns About Tonsillectomy	Jul 01	
Question About Spinal Fusion Surgery	Aug 01	
Small Potty	Aug 01	Oct 01
Nail Picking	Aug 01	
Emotional Problems in a 5-year-old	Aug 01	
Information About Opsoclonus Myoclonus	Sep 01	
Jarcho Levin Syndrome	Sep 01	
Looking for a Bed	Sep 01	Dec 01
Sweating Problem	Sep 01	Dec 01
Test to Measure Learning Disabilities	Oct 01	
Bathtub Dilemma	Oct 01	
Feeling Isolated	Oct 01	
Daughter has Episodes of Unusual Behavior	Oct 01	
Severe Cramping	Oct 01	
Psoriasis	Oct 01	
Looking for a Reading Program for Nonverbal Child (listed as a Respond)	Oct 01	

Topic	Search	Respond
Assistance from Airline	Nov 01	
Daughter Needs Someone to Talk to	Nov 01	
Orthodonture for a Child with Down Syndrome	Nov 01	
Mother and Child Both Have Disabilities	Nov 01	
Looking for Brushes	Nov 01	Dec 01
Hyperacute Hearing	Nov 01	
Multiple Diagnosis	Dec 01	
Picky Eater	Dec 01	
Looking for Programs for People with Brain Injury	Dec 01	
Falling Safely	Dec 01	
Toileting at School	Dec 01	

Instant S & R

Topic	Search
OCD and Puberty	Feb 01
Visual Learning Disability	Mar 01
Problems from Seizure Medication?	Mar 01, May 01
Is Being Picked on a Problem?	Apr 01
Shoes that Fit Over AFOs	Apr 01
Child Won't Keep Clothes On	Apr 01
Difficulty Speaking	May 01, Jul 01
Car Seat	May 01
Braille Printer	Jun 01
Daughter Missing Out	Jun 01
Drinking from a Straw	Jul 01
Should Son be Evaluated by School or Outside Professional?	Jul 01
Laparoscopic Nissen Fundoplication	Aug 01, Oct 01, Nov 01
Twins—One with Down Syndrome, One Without	Aug 01
Daughter is Depressed and Angry	Sep 01
Obesity in a 2-year-old	Sep 01
Washing Hair	Oct 01
Distractibility in a Child Who had Meningitis	Nov 01
Motivation Issues	Dec 01

NO
APOLOGIES
FOR
RITALIN

No Apologies For Ritalin ◦ By Vidya Bhushan Gupta, MD ◦ EP8012AD- $19.95

Despite its name, No Apologies for Ritalin is aimed at educating parents of children with ADD by presenting all the treatments available for the disorder.

The first half of the book is a look at what ADD is: the medical aspects, how it is diagnosed, and what causes it. Anecdotes of children diagnosed with the disorder and a discussion of how doctors arrive at their diagnoses begin the book. Issues that parents must deal with, such as understanding and coming to grips with the diagnosis of ADD, whether ADD is a product of bad parenting style, ADD's occurrence with other disorders, and who is most at risk are discussed in this section as well.

Section 2 presents the pros and cons of all treatment options, both conventional and alternative, including non-drug therapies such as psychotherapy and behavior modification. The author, Vidya Bhushan Gupta, MD, MPH, FAAP, writes in his Foreword, "I have discussed the controversy surrounding the use of Ritalin and tried to dispel myths surrounding ADD and Ritalin: 'ADD is not a disease; it is simply a difference of temperament;' 'ADD is due to poor parenting;' 'Ritalin is a mind-altering drug like speed;' 'Don't give Ritalin to your children because they will get hooked on it.'" He explains that his purpose for writing the book is so that "parents of children with ADD will not blame themselves for their child's predicament and will be able to use all the available treatments, including Ritalin, without guilt."

The book offers insights into other issues regarding ADD as well, including: who should treat the disorder and what the goals of that treatment should be; suggestions for parents on dealing with their child's ADD; whether children grow out of their ADD; and how to de-emphasize the negative labels of the disorder by recognizing and building on the strengths of children diagnosed with it.

……

Patient Persistence

Patient Persistence ◦ By Adele M. Gill ◦ EP8004GN-$19.95

Patient Persistence celebrates the ability of people to overcome obstacles to achieve their goals. Author Adele Gill invited individuals from every background to tell their stories of "hope, courage, hard work, and endurance related to health, disability, relationships, family, ministry, career, accomplishment and challenge."

Ms. Gill is a certified disability analyst/fellow with the American Board of Disability Analysts, and an advocate of inspirational/motivational self-help. She writes, "Patience and persistence are qualities that are vital to the discovery of our finest, God-given gift; the resilient 'Indelible Human Spirit.' These innate qualities propel people and enable them to do great things and overcome significant hurdles."

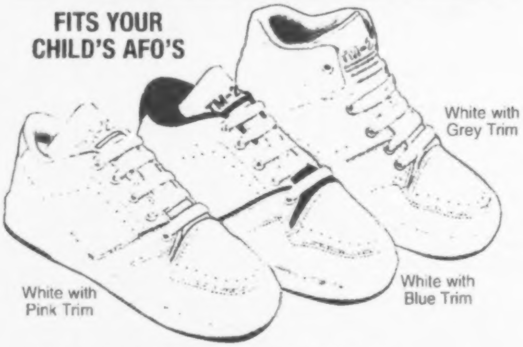
Patient Persistence is both motivational and inspirational, offering help and hope to anyone who feels that his or her life is out of control, or that things have gotten so bad that there will never be a way to make it better.

BOTH OF THESE BOOKS ARE AVAILABLE THROUGH THE EP LIBRARY BY CALLING 1-800-535-1910, OR BY VISITING THE WEBSITE AT WWW. EPLIBRARY.COM

TM2000
SERIES
by MARKELL

Order Online at www.markellshoe.com

FITS YOUR
CHILD'S AFO'S



The TM 2000 Series has the following features:

- Symmetrical straight last.
- Added depth - 3/16" (5mm) deeper than our conventional straight last shoes, to accommodate orthotics, AFO's and internal modifications.
- Extended contours firm enough to provide support and stability.
- Whole and half sizes from Infants' 5 to Youths' 4.
- Widths - A choice of Medium and Wide.
- Removable cushioned insoles

M.J. MARKELL SHOE CO., INC.
504 Saw Mill River Road, P.O. Box 246, Main Station, Yonkers, N.Y. 10702
TEL: (914) 963-2258 • FAX: (914) 963-9293

Circle #39 or visit www.eparent.com/adinfo

Hyperbaric Oxygen Therapy [HBOT] is the breathing of 100% oxygen under increased atmospheric pressure. The effects of HBOT on the organs and tissues of the body are multi faceted.*

South Florida Center for H.O.P.E. offers a clean and bright friendly atmosphere, using only state-of-the-art equipment. Our doctors and technicians are trained by a UHMS accredited course and certified in HBOT by the NBDHMT. They come with many years experience in the field of hyperbaric medicine.

* Hyperbaric Medicine Practice
Eric P. Kindwall, M.D.

WE OFFER H.O.P.E.
[HYPERBARIC OXYGEN PRODUCING ENVIRONMENT]

CONDITIONS TREATED WITH HBOT
- *CEREBRAL PALSY [CP]*
- *TRAUMATIC BRAIN INJURY*
- *ANOXIC ISCHEMIC ENCEPHALOPATHY (AIE)*
- *NEAR DROWNING*
- *STROKE [CVA]*
- *MULTIPLE SCLEROSIS [MS]*
- *NON-HEALING WOUNDS**
- *RADIATION INJURY**
- *AUTISM*

* *CURRENTLY APPROVED BY FDA*

ANCILLARY SERVICES
- *INTEGRATED MANUAL THERAPY*
- *PHYSICAL THERAPY*
- *OCCUPATIONAL THERAPY*
- *SPEECH THERAPY*
- *BIO RESONANCE THERAPY*
- *NEURO-BIOFEEDBACK*

South Florida Center for H.O.P.E
1898 H West Hillsboro Blvd.
Deerfield Beach, FL 33442
[954] 571-9392
Toll Free: [866] 473-HOPE

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

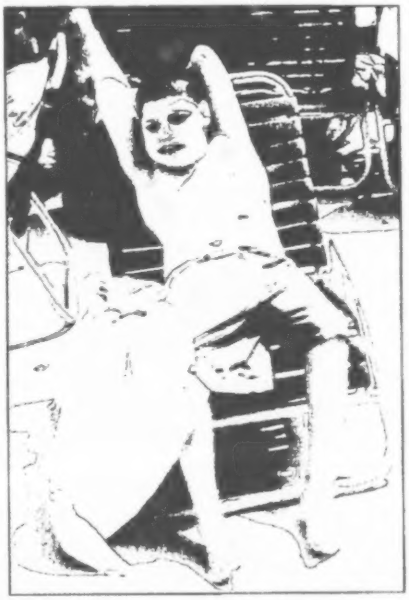
Circle #50 or visit www.eparent.com/adinfo

familiar faces

DEENA

Deena Carman Giriyappa, 5, "is the sweetest little girl you will ever meet," says her caretaker Laura Rabida. She has cerebral palsy and brachial plexus. She is a fun, lovable, huggable, happy and determined girl with a great sense of humor. Her smile is so contagious, you can't help but love her. Deena receives many therapies and uses an alpha talker to communicate. She has touched many lives. As she continues to grow, she will touch many more. Deena lives with her loving parents, Eleanor and Pradeep.

JAMES



James Oliver, 13, is pictured taking a break on a summer day. He loves the outdoors, horses, music and swimming. He keeps busy by taking adapted swimming lessons.

JEREMIAH

Jeremiah Francis Caparosa, 16 months, has just received his first haircut at the barber's! His mother **Mona** (pictured holding him) is very proud of him. He has two brothers, James and Nicholaus; his best buddy, Daddy; and Roxy Girl, the family dog. Jeremiah has Down Syndrome and is doing very well.

DANIEL

Daniel Seering, 5, and his sister **Rebecca**, 7, last Easter after an egg hunt. Daniel has fragile X syndrome and has also been diagnosed with mental retardation, autism, ADHD and sensory integration disorder. Daniel likes to play his own versions of hide-and-seek and tag. He also likes to watch TV, look at books, put puzzles together, go for rides in the car, eat out and ride the swings. Daniel receives speech and occupational therapies. He lives at home with his sister and parents, Joe and Kathy. *For more information about fragile X syndrome, please visit: http://www.FragileX.org*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (EXCEPTIONAL PARENT), 65 E. Route 4, River Edge, NJ 07661. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be returned.**) On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

CHILDREN'S NEUROBIOLOGICAL SOLUTIONS

What About the Children?

By Terry Boisot

Palmer Clay Richmond was only two days old when he was diagnosed with a seizure disorder. Eight days later, he underwent two emergency surgeries to remove damaged intestines. By two and a half years old, he had been at death's door four different times. Palmer is now 6 years old; his liver is damaged from the long-term use of anti-convulsants and other medical interventions, and doctors want to remove his enlarged spleen.

"I don't think he would survive the surgery," says his mother, Fia.

Palmer, medically fragile, chronically ill and severely disabled, has endured much at the hands of conventional medicine. Fia said, "We are told that for whatever ails us there is a pill, radioactivity or surgeries to cure us. And if one is unfortunate enough to have an ailment that is not yet curable by our modern medicine, they give no tangible answer, just a turn of their brow and the suggestion of more dope."

Conventional medicine has no "magic bullet" for Palmer. Its interventions seem only to compound, rather than resolve, the enigmas of his physical condition. Time after time he has been sentenced to more surgeries, more machinery, more drugs and more artificial foods, with no hope of ever healing.

Upon Fia's entrance into motherhood and the medical community she was hit hard with the feeling that the world wasn't open to possibilities that would give Palmer comfort in his physical body while at the same time honoring his inherent value, dignity and soul.

Some of society may look at Palmer and see a tragic life, without a voice to be heard, but his mother can hear her son's voice. "I see beyond his physical condition and see who his soul is. No matter how hurt children like Palmer are, they have voices. They are a part of the collective unconscious and soul of the world, and they need to be heard."

In her quest to save her son, Fia opted to create her own story for Palmer—one that conventional medicine could not—one of healing.

This story of healing began one day more than three years ago, as Fia and her husband, Phil, were sitting in the kitchen contemplating the uniqueness of Palmer's physiology and the challenge his health presented to the laws of conventional medicine. It was that day Fia said somewhat jokingly, yet very seriously, "Palmer needs a scientist, not a doctor." The sound of her own words gave her hope.

M. Morton Mitchell, CNS Foundation treasurer, supports research for the benefit of his granddaughter Molly, 4, who is developmentally delayed because of an undiagnosed neurological disorder.

Fia began her journey to obtain more than a casual understanding of biomedicine, the major advances researchers have made in their understanding of fundamental life processes and the use of our own body's mechanisms to repair itself.

"The field of neuroscience, the study of the brain, has transformed our knowledge within these last 10 years, revealing exciting new discoveries that the brain, like other parts of our body, has the potential of healing," according to Fia.

Ten years ago scientists did not believe this could happen; recent advances in biomedicine are phenomena that can be compared with Galileo saying the sun, not the earth, is the center of the universe.

One of the first books Fia read about progress being made in the field of neuroscience was *Inside the Brain*, in which the author, Ronald Kotulak, quotes Dr. Wise Young, "The key to all this is the fact that the vast majority of scientists now believe that the central nervous system can regenerate. They are now convinced that it's only a matter of time before we discover how to make it grow."

As her interest in neuroscience increased, Fia became more aware of articles on the subject appearing in the media, and noted that Dr. Evan Snyder's name appeared regularly. Dr. Snyder, a pediatric neurologist and neonatologist at Boston Children's Hospital and Harvard Medical School, rocketed to prominence ten years ago when he was one of the first to isolate and grow stem cells and suggest that using them might heal brain disorders.

Fia became impressed with Dr. Snyder's work, inspiring her to contact him. After

CNS vice president Sue Ellen Strong (second from right) with her family (left to right): Christopher, Carl and Katherine. Katherine, 4, sustained significant brain damage at four weeks of age due to a viral infection or a vaccine reaction.

spending two hours on the phone with him, she was also impressed with his humanity, and his well-thought-out responses to her questions. The Richmonds decided to raise funds to help support Dr. Snyder's research, and made an appointment to meet with him.

Upon the suggestion of friends, they also arranged a meeting with Dr. Jeffrey Macklis, another neuroscientist and a colleauge of Dr. Snyder. Dr. Macklis' primary interest is human neurogenesis, that is, the birth of new cells of the nervous system, called neurons. It had been a long-held understanding that adult human brains cannot replace dead neurons, leaving scientists with the belief that brain damage is irreversible. However, recently, research has demonstrated that human brains do generate new cells after all, opening up tremendous possibilities for healing.

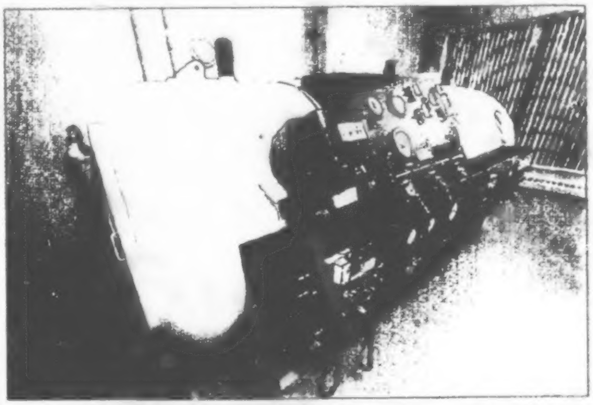
As Fia recalls the meeting with Dr. Snyder and Dr. Macklis–a meeting that lasted for hours–it was the first time her questions had not been met by the frown and scowl that had become an expected part of what conventional medicine had to offer Palmer. This time, there were answers. "Light bulbs go off in their minds and they circumnavigate a concept—looking at all directions of the problem. Both doctors were extremely respectful and for me it was like hitting a pot of gold."

By the time the meeting was over, the Richmonds knew they had just met two incredible people who held in their minds, their research, and their optimism for the near future hope for Palmer's healing. On the

continued on page 74

HYPERBARIC OXYGEN THERAPY

Brain Injuries ~ Cerebral Palsy ~ Near Drowning ~ Stroke ~ MS ~ Lyme Disease



- ☑ Combined 30+ years experience in the hyperbaric field.
- ☑ Care-giver accompanies patient in MULTI-place chambers.
- ☑ NEW chambers with AIR CONDITIONING, entertainment systems and comfortable seating.
- ☑ Experienced Medical Directors are MD's.
- ☑ Facilities are open 7 days/week.
- ☑ Friendly staff makes the experience personal, comfortable, and pleasant.

Two state-of-the-art facilities for your convenience:

Northeast U.S. & Canada

TORONTO HYPERBARIC INC.

Mississauga, Ontario, CANADA
Phone: 905-306-0770
Email:help@torontohyperbaric.com
www.torontohyperbaric.com

Southern U.S.

HyperTec

Olney, Texas, USA
Toll Free: 1-800-218-3588
Email: bbailey@hypertec.ws
www.hyperbaric-health.com

EP neither endorses nor denies the effectiveness of this therapy. For our Editor-in-chief statement see our Contents page.

Circle #55 or visit www.eparent.com/adinfo

continued from page 73

way home, the Richmonds had a serious conversation about a foundation that would support a collaboration of some of the most brilliant minds in the scientific community to focus not on a disease, but on the brain itself.

It didn't take long before that conversation grew into the formation of Children's Neurobiological Solutions Foundation. CNS is a collaboration of parents and eleven world-renowned neuroscientists and clinicians, including Dr. Snyder and Dr. Macklis. They believe that emerging discoveries involving the brain and its ability for self-healing, together with an understanding of the biological states of human development, "are our gateway into a society that will inherit the potential to repair and regenerate the damaged brain, securing a future filled with possibilities for our present and future children."

The CNS mission, "is to orchestrate cutting edge, collaborative research with the goal of expediting the creation of effective treatments and therapies for children with neurodevelopmental abnormalities, birth injuries to the nervous system, and related neurological problems." In addition, CNS strives to provide families and health care providers with user-friendly access to state-of-the-art information and education supporting their decision-making processes.

With Fia's commitment to heal her son also comes a commitment to remaining sensitive and concerned about the disability rights movement, and how the presentation of the work of CNS has an impact on people with disabilities. "I believe that all people have special needs requiring active compassion; one in particular is the need not to be given a limiting label, but rather to be honored in their individuality."

Within its core values, CNS respects, honors and supports the accomplishments of those that have shed light on the inherent value and dignity of people with disabilities. It believes that every individual has the capacity to make a difference and should be respected as a whole–body, mind, and spirit.

As Fia explains, "I'd like Palmer to experience comfort in his physical body. I'm talking about healing his body, not his soul. His soul is beautiful and I would never want to change it," [Fia Richmond,] August 2001.

Fia Richmond can be emailed at cnsfoundation@home.com or can be contacted at:

Fia Richmond,
Founder and President
Children's Neurobiological Solutions
1726 Franceschi Road
Santa Barbara, CA 93103
866.267.5580 or 805.965.8838

Visit the web site of Children's Neurobiological Solutions Foundation at http://www.cnsfoundation.org EP

Never in my Wildest dreams...

"WHEN I FIRST CAME TO CROTCHED MOUNTAIN OVER 10 YEARS AGO, activities that were second nature prior to the automobile accident were challenging tasks. Today I am a college graduate and also have my drivers license.

Never in my wildest dreams would I have been able to do half of what I've achieved without the encouragement and help that I received at Crotched Mountain! I want to thank everyone at Crotched Mountain for helping me get my life back!"

—Brent Reagan '93
Crotched Mountain School

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

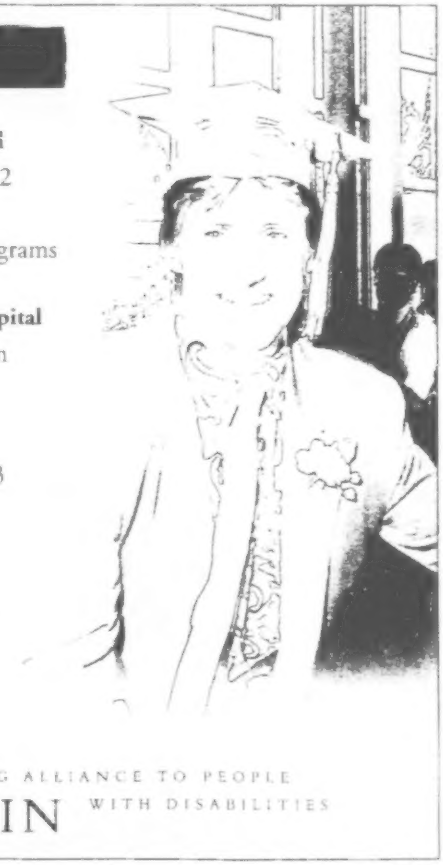
Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@cmf.org

CROTCHED MOUNTAIN

OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #23 or visit www.eparent.com/adinfo



Information and support for the special needs community

PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP MAGAZINE

SYMBOL OF EXCELLENCE · EP · PARENT · COMMUNITY · CARE

Welcome Resources Technology Edu/Toys Healthcare Subscribe

eparent.com

New! Visit the EP Web site, EParent.com, and discover…

TOYS—The new eToys Web site (www.etoys.com) teams with EP's Web site, EParent.com (www.eparent.com) to offer ideas, information and imaginative toys for families with kids who have special needs. When parents, teachers or caregivers shop at eToys and visit the co-branded EParent.com site, they'll find hand picked toys and games, plus featured articles from EP Magazine. The site also features direct links to the EParent.com shop at eToys, and eToys products recommended by experts or reviewed by organizations chosen by EP Magazine.

EDUCATION—EParent.com's newly-constructed Education channel (EDU/TOYS tab) yields a wealth of current articles on topics such as IDEA, IEPs, assistive technology, transitioning and inclusion. These are supplemented by a growing directory of schools, camps & residences, which can be found in the "Directories" link of the "Resources" channel.

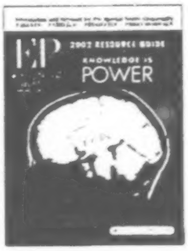
ON-LINE ARCHIVES—Now, EParent.com users can preform keyword searches through our on-line archives and purchase articles which have appeared, as far back as in the eighties, in EP Magazine (recipient of awards from Folio:The Magazine for Magazine Management, Easter Seals, Consumer Healthcare Group). These include classic pieces on such subjects as early childhood, rare disorders, technology, education, medical research update, transitioning, travel, all of which have distinguished EP Magazine through the years.

MORE TO COME IN 2002—You can also click through our EP Library (www.eplibrary.com) which contains books, videos and software encompassing almost 50 specific and general categories, with more than 650 titles. Of course, we will continue to refresh and improve EParent.com in 2002, and look forward to receiving your comments and suggestions. Log on and find out what we are all about!

EP
Exceptional
Parent

BOBBY
Click here for our
Text only site

NOW
SUBSCRIBE
ON-LINE



National
Resource
Directory

WWW.EPLIBRARY.COM
EP LIBRARY
THE SPECIAL NEEDS BOOKSTORE

www.eparent.com

AUTISM AND THE MMR VACCINE

The National Institute of Child Health and Human Development (NICHD)

Some parents and families of children with autism believe that the Measles/Mumps/Rubella (MMR) vaccine caused their children's autism. These parents report that their children were "normal" until they received the MMR vaccine. Then, after getting the vaccine, their children started showing symptoms of autism. Because the symptoms of autism begin to occur around the same time as the child's MMR vaccination, parents and families see the vaccine as the cause of the autism. However, just because the events happen around the same time does not mean that one caused the other. Although children receive many other vaccines in addition to the MMR vaccine, these other vaccines have not been identified as possible causes of autism.

These parents' beliefs and observations were reinforced by a small study of bowel disease and autism, published by Wakefield and his colleagues in 1998. The study's authors suggested that there was a link between the MMR vaccine and autism. This study did not include scientific testing to find out if there was a link. The authors relied on the reports of parents and families of 12 children with autism to make their suggestion. The study did not provide scientific proof that there was any link. Since this study was published in 1998, a number of other studies have also been published that suggested a link between the MMR vaccine and autism, but none of these provide scientific proof of such a link. To date there is no definite, scientific proof that any vaccine or combination of vaccines can cause autism.

Why do many doctors and scientists believe that the MMR vaccine does not cause autism?

In 2000 the Institute of Medicine (IOM) at the National Academy of Sciences, at the request of the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), conducted a review of all the evidence related to the MMR vaccine and autism. This independent panel examined completed studies, on-going studies, published medical and scientific papers, and expert testimony to assess whether or not there was a link between autism and the MMR vaccine. The IOM concluded that the evidence reviewed did not support an association between autism and the MMR vaccine. This and other conclusions from the IOM review were released in April 2001 (Immunization Safety Review Committee 2001).

Also in 2000, the American Academy of Pediatrics (AAP), a professional organization for pediatricians, held a conference on the MMR vaccine and autism. Parents, scientists, and practitioners presented information on this topic to a multidisciplinary panel of experts. Based on its review, the AAP also found that the available evidence did not support the theory that the MMR vaccine caused autism or related disorders. The AAP policy statement appeared in the May 2001 issue of *Pediatrics*.

In 1999, Taylor and colleagues published a study that argued against the suggested link between autism and the MMR vaccine suggested in the Wakefield study. Taylor's study looked at all the known cases of autism spectrum disorder (ASD) in children living in certain districts of London who were born in 1979 or later. Researchers then matched the ASD patients with an independent registry of vaccinations. The results of this study showed that:

❑ The number of ASD cases had increased steadily since 1979, but there was no sharp increase in the number of cases after doctors started using the MMR vaccine in 1988.

❑ Children showed symptoms of ASD and were diagnosed with ASD at the same ages, regardless of whether they were vaccinated before or after 18 months of age. This finding is important because if the MMR vaccine caused ASD, the children who were vaccinated earlier would show symptoms earlier.

❑ By age two, vaccination coverage (the number of children who received vaccines) among children with ASD was nearly the same throughout the region as vaccination coverage for children the same age who did not have ASD. If the MMR vaccine and autism were linked, then a greater number of children who had been vaccinated throughout the region would have ASD.

❑ The first signs of autistic behavior or first diagnosis of ASD were no more likely to occur in time periods following the MMR vaccine than in other time periods.

Also in 1999, the United Kingdom's Committee on Safety of Medicine examined hundreds of reports collected by lawyers of patients with autism and similar disorders that families said they developed after receiving the MMR or MR vaccine. After a systematic, standardized review of the case information, the Committee found that the information did not support any link between vaccines and autism. Based on the evidence, the Committee concluded that there was no cause for concern about the safety of MMR or MR vaccines.

A study done in Sweden in 1998 showed no evidence of association between the MMR vaccine and autism. The study compared the number of autism cases in children from two Swedish towns before 1982, when local doctors first started using the MMR vaccine, and after 1982. The results showed no difference in the towns' rates of autism.

Another study, done in England in 1997, looked at any possible link between the measles-specific vaccine (one part of the

MMR vaccine) and different problems that result from damage to the nervous system, such as learning disabilities and behavior problems. These researchers found no proof that the measles vaccine was in any way linked to long-term damage to the nervous system.

Is there any research going on to find out if the MMR vaccine is linked to autism?

The NIH is doing a number of things to look into the claims about MMR vaccines and autism:

The Network on the Neurobiology and Genetics of Autism: Collaborative Programs of Excellence in Autism (CPEA), funded by the National Institute of Child Health and Human Development (NICHD) and the National Institute on Deafness and Other Communication Disorders (NIDCD) with additional funding from the CDC, are working together to study autism and the MMR vaccine. This research will examine people diagnosed with autism who seemed to develop normally, but then started to show autistic symptoms. This type of situation is called "regression." To learn as much as possible about these patients, researchers will compare them to people who do not have autism, and to people who showed autistic symptoms since birth, called "classic" autism. CPEA researchers will compare vaccination records to see if the onset of autism was associated with receipt of MMR and other vaccines. Lab tests will then look for any evidence of persistent infections that could be related to the MMR vaccine.

The NICHD is also working with other NIH Institutes, the CDC, the Environmental Protection Agency (EPA) and other federal agencies to conduct a large, long-term study of the effects of the environment on children's health. This study will follow 100,000 children from before birth to age 20 to track their growth and development, their genetic blueprints and environmental factors that they encounter. Researchers hope to establish or rule out links between a variety of environmental events and normal and abnormal development, such as autism, asthma, and other disorders that have shown dramatic

continued on page 78

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

HYPERBARIC OXYGENATION FOR THE COMATOSE CHILD

There is some hope for the comatose child suffering from severe brain injuries, cerebral palsy, or anoxic encephalopathy. Children with Glasgow Coma scales from 3-5 present tremendous financial and emotional burdens, since these little ones may live for many years. When considering care of tracheotomy, gastric tube for feeding, physical therapy, occupational therapy, speech therapy, nursing care, recurrent hospitalizations, medications, vans, and modifications to the home, expenditures may represent multi-million dollars.

Intensive hyperbaric oxygenation is no miracle, but it provides some hope. In certain instances the child is able to communicate verbally, by computer or word board. Eighty percent have the G-tube removed and seventy percent have the tracheotomies closed. Frequently, bowels become normal and nutrition is re-established. Routine monthly medications are reduced and hospitalizations are markedly decreased. Although few children will return fully to society, substantial improvements will give them a better quality of life in addition to a ninety percent reduction in overall costs.

For more information on hyperbaric oxygenation therapy and life planning, call the Ocean Hyperbaric Neurologic Center at (800) 552-0255.

Coming Soon!

Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child..

by R. A. Neubauer, M.D.

Dr. Neubauer's new book is a complete guide written for the professional as well as the caregiver of exceptional children. The book describes the latest information on hyperbaric oxygenation therapy including improved brain function as visualized through functional imaging. Clinical and scientific data along with references are included.

Call 1-800-552-0255 to order

(800) 552-0255
• Call for free video & information

For more information visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #42 or visit www.eparent.com/adinfo

continued from page 77

increases in new cases within the past few years. The study is currently under design.

Another NIH Institute, the National Institute of Neurological Disorders and Stroke (NINDS), is conducting a retrospective case-control study to identify any molecular markers in neonatal blood of children with autism, with support from the California Department of Health Services and the Division of Bioengineering and Physical Science (DBEPS) at the NIH.

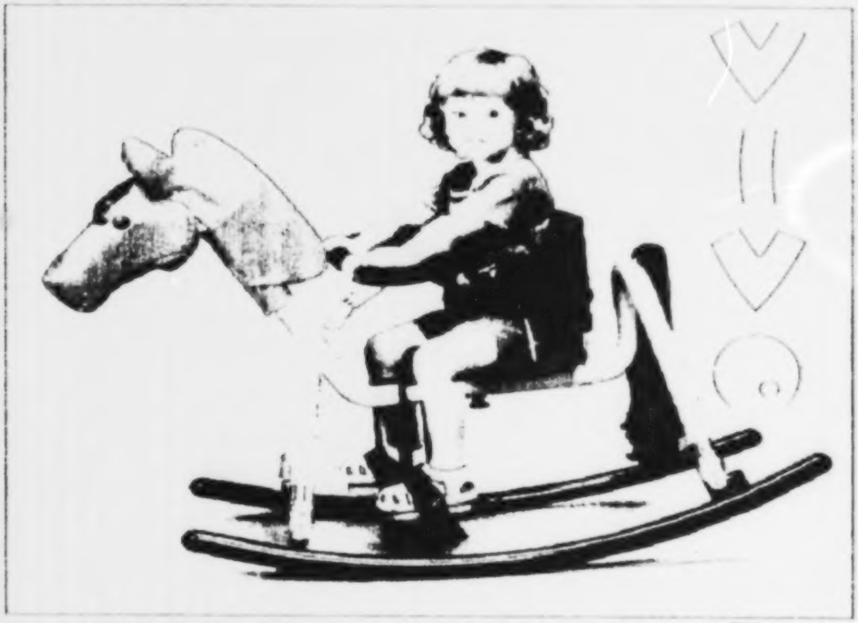
In 1998 the NIH, led by the NICHD and the NINDS, sponsored a conference on ASDs. These and other NIH Institutes formed an expert panel, which also included 15 professional organizations and three parents' groups, and began a review of more than 2,500 scientific articles to develop a system for diagnosing ASDs. The panel published its findings in the Journal of Autism and Developmental Disorders in 1999. In 2000, the panel's report was adopted as a practice parameter by the American Academy of Neurology and the Child Neurology Society. Practice parameter screening and diagnosis of autism gives doctors and other health professionals the first standardized method for diagnosing autism and ASDs based on scientific evidence.

In addition, the NIH is in the process of implementing the autism aspects of the Children's Health Act of 2000. This Act, which was signed into law in October 2000, charges the NIH with the "expansion, intensification, and coordination of activities of the NIH with respect to research on autism." All of the NIH Institutes that fund autism research are working together to establish "Centers of Excellence" to focus on autism research. In addition, the NIH will form a committee with representatives from parents' groups and other federal agencies to coordinate autism research activities throughout the federal government and to enhance efforts to educate doctors and other health care professionals, parents and direct support professionals about autism.

Aren't the diseases prevented by the MMR vaccine mild, when compared to the life-long symptoms of autism?

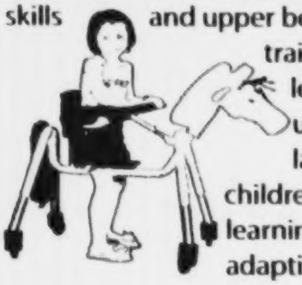
The diseases that the MMR vaccine prevents–measles, mumps, and rubella (also called German measles)–are actually very serious. Many times, the symptoms and effects of these diseases are just as serious and life-long as the symptoms of autism; in some cases, they result in death. If people stop getting vaccines, the incidence of these diseases will increase, as will the number of deaths and serious health problems.

Measles is a life-threatening disease that spreads quickly and easily. Before the vaccine was available in the U.S., nearly everyone who was exposed to measles got the measles,



R.E.A.L. Design Introduces VIVO™
The New Multi-Therapy Pony

Children will love VIVO, the playful, spirited little pony with the head that bounces when moved and a colorful beaded tail. Parents and therapists will appreciate the valuable skills children gain by playing on VIVO because it functions as a balance rocker or gait trainer by simply interchanging the legs which snap on and off easily. As a rocking horse, VIVO promotes balance reaction skills and upper body postural development. As a gait trainer, it provides incentive for a child to learn ambulation skills. The soft upholstered seat back, with molded laterals, is height adjustable to position children comfortably and securely for rocking or learning to walk. Accessories are available for adapting VIVO to a child's positioning needs.



R.E.A.L. DESIGN 1.800.696.7041 Fax: 1.315.429.3071
www.realdesigninc.com

Circle #44 or visit www.eparent.com/adinfo

three to four million cases each year. The symptoms of measles include a rash, high fever, cough, runny nose, and watery eyes. But if not treated, these seemingly mild symptoms can lead to conditions such as pneumonia, seizures, and water and swelling around the brain. For one in 500-1,000 people, measles causes death. High levels of immunization in the U.S. have led to a 99 percent decrease in measles cases since doctors first started using the vaccine. But in poorer countries of the world, where vaccines aren't as common, nearly 900,000 people died in 1998 from causes related to measles.

Mumps, which the MMR vaccine also protects against, was a major cause of deafness in children before doctors started using vaccines to prevent it. Even though it tends to be mild in children, mumps is dangerous for adults, with side effects that can include paralysis, seizures, and fluid in the brain. Before the vaccine for mumps was available, there were about 212,000 cases each year in the U.S., while in 1998 there were only 606 cases.

The last disease prevented by the MMR vaccine, rubella, is harmful to pregnant women and their developing babies. If a pregnant woman gets rubella, her baby may develop a life-long condition that includes heart defects, mental retardation, and deafness. In some cases, the baby's condition is so severe that the baby dies. In 1964-65, before the vaccine for rubella was available, 20,000 babies were born to mothers who had rubella during their pregnancies. Of those 20,000, 11,600 were deaf, 3,580 were blind, and 1,800 were mentally retarded.

Note: Disease statistics cited in this document came from the National Institute of Allergy and Infectious Diseases (NIAID) at the NIH and the National Immunization Program (NIP) at the CDC.

Should my child have the MMR vaccine?

Both the CDC and the AAP recommend that children receive two doses of the MMR vaccine as long as they have no known health problems that would prevent the vaccine from being effective. The CDC and AAP immunization schedules recommend that the first dose be given at age 12 to 15 months, while the second dose should be given at either four to six years of age or 11 to 12 years of age.

Allergies, immune system diseases like HIV, or other sicknesses can interact with a vaccine to make it less effective. These interactions can sometimes cause other health problems. If your child is sick, your doctor may delay the vaccination until your child is healthy. For example, a child with a fever should not have a vaccination until the fever is gone. Make sure you give a complete description of your child's current health and health history to your child's doctor at every visit, so he or she can help you make an informed choice about the timing of your child's vaccinations.

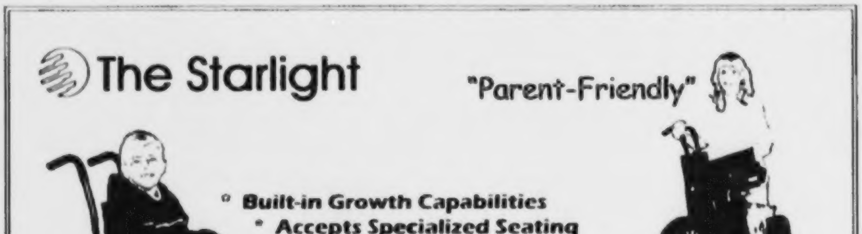
continued on page 80

For more information

For more information on autism and autism research, including studies involving vaccines and autism, contact the NICHD Clearinghouse at:
Mail: PO Box 3006, Rockville, MD 20847
Phone: 1-800-370-2943 • Fax: 301-984-1473
Email: mail to NICHDClearinghouse@mail.nih.gov
Internet: www.nichd.nih.gov/autism

For more information on vaccines and vaccine safety, contact the National Immunization Program (NIP) at the CDC, at 1-800-232-2522 (English) or 1-800-232-0233 (Spanish), or visit the NIP web site at http://www.cdc.gov/nip/.

This piece has been excerpted from NIH Publication No. 01-4963, June 2001.
U.S. Department of Health and Human Services
Public Health Service
National Institutes of Health
National Institute of Child Health and Human Development



The Starlight
"Parent-Friendly"
- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW
- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made in U.S.A.

Circle #30 or visit www.eparent.com/adinfo

Adaptivemall.com™

Shop
On-line!

Tim's daughter Carrie, a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment..........and OT/PT on-line SIZE HELP facilitates your selection.

Tim Bergeron has more than 20 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-3407

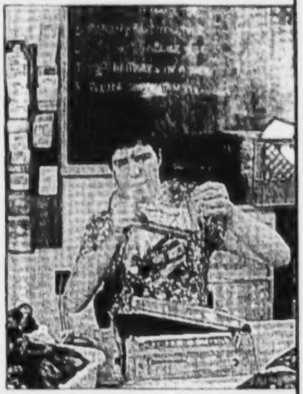
Tim Carrie

Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #20 or visit www.eparent.com/adinfo

PERSONAL INDEPENDENCE

THE EVERGREEN CENTER prepares students to lead meaningful lives in the community. Through an individual educational program combining basic skills and behavior development,our students learn to lead more independent lives as integrated members in the community.



Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631

Serving students with developmental, medical and behavioral needs since 1981.

Circle #28 or visit www.eparent.com/adinfo

continued from page 79

Citations

Filipek PA, Accardo PJ, Ashwal S, Baranek GT, Cook, Jr EH, Dawson G, Gordon B, Gravel JS, Johnson CP, Kallen RJ, Levy SE, Minshew NJ, Ozonoff S, Prizant BM, Rapin I, Rogers SJ, Stone WL, Teplin SW, Tuchman RF, and Volkmar FR. (1999). The screening and diagnosis of autism spectrum disorders. Journal of Autism and Developmental Disabilities, 29(6):439-484.

Filipek PA, Accardo PJ, Ashwal S, Baranek GT, Cook, Jr EH, Dawson G, Gordon B, Gravel JS, Johnson CP, Kallen RJ, Levy SE, Minshew NJ, Ozonoff S, Prizant BM, Rapin I, Rogers SJ, Stone WL, Teplin SW, Tuchman RF, and Volkmar FR. (2000). Practice parameter: screening and diagnosis of autism, Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. Neurology, 55:468-479.

Gillberg C and Heijbel H. (1998). MMR and autism. Autism, 2:423-4.

Halsey N, Hyman S, and The Conference Writing Panel. (2001). Measles-mumps-rubella vaccine and autistic spectrum disorders. Pediatrics, 107(5): e84-107.

Horvath K, Papadimitriou JC, Rabsztyn A, Drachenberg C, and Tildon JT. (1999). Gastrointestinal abnormalities in children with autistic disorders. Journal of Pediatrics, 135(5):559-563.

Immunization Safety Review Committee, Board on Health Promotion and Disease Prevention, Institute of Medicine. (2001). Immunization safety review: measles-mumps-rubella vaccine and autism. Stratton K, Gable A, Shetty P, and McCormick M (Eds.). Washington, DC: National Academy Press.

Kawashima H, Mori T, Kashiwaga Y, Takekuma H, Hoshika A, and Wakefield A. (2000). Detection and sequencing of measles virus from peripheral mononuclear cells from patients with inflammatory bowel disease and autism. Digestive Disease Science, 45(4):723-729.

Medicines Commission Agency/Committee on Safety of Medicines. (1999). The safety of the MMR vaccine. Current Problems in Pharmacovigilance, 25:9-10.

Miller D, Wadsworth J, Diamond J, and Ross E. (1997) Measles vaccination and neurological events. Lancet, 349:730-731.

O'Leary JJ, Uhlmann V, and Wakefield AJ. (2000). Measles virus and autism. Lancet, 356:772.
Singh VK, Lin SX, and Yang VC. (1998). Serological association of measles virus and human herpes virus-6 with brain autoantibodies in autism. Clinical Immunology and Immunopathology, 89:105-108.

Taylor B, Miller E, Farrington CP et al. (1999). Autism and measles, mumps, rubella vaccine: no epidemiological evidence of for a causal association. Lancet, 353:2026-2029.

Wakefield AJ, Murch S, Anthony A, et al. (1998). Ileal lymphoid nodular hyperplasia, non-specific colitis, and regressive developmental disorders in children. Lancet, 351:637-641.

Wakefield AJ, Anthony A, Murch SH, Thompson M, Montgomery SM, Davies S, O'Leary JJ, Phil D, Berelowitz M, and Walker-Smith JA. (2000). Enterocolitis in children with developmental disorders. American Journal of Gastroenterology, 95:2285-2295. EP

292

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

EXCEPTIONAL PARENT

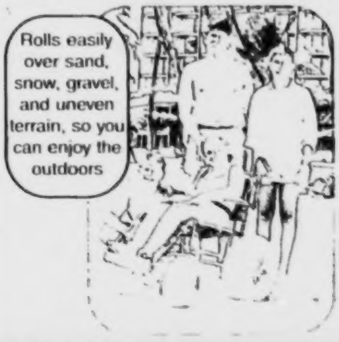
Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores All Across America. Every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books. $4.95 Cover Price.

Circle #1

Natural Access™

Expand your horizons with the Landeez All-Terrain Wheelchair!


Rolls easily over sand, snow, gravel, and uneven terrain, so you can enjoy the outdoors

For more info 800-411-7789 or visit www.landeez.com

Circle #2

DISCOVER
FREEDOM

FREEDOM

"GIVE US A NEED, WE WILL FIND THE CONCEPT!"

FREEDOM CONCEPTS INC.
P.O. Box 45117 RPO Regent Ave West
Winnipeg, Manitoba, Canada R2C 5C7
PHONE: 1-800-661-9915 FAX: 204-654-1149
www.freedomconcepts.com

Circle #3

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:

1-800-442-6992 or www.abilitycamp.com

Circle #17 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

To start your subscription to EP today, fill out the card near the front of this magazine or log on to www.eparent.com

Personalized Interdisciplinary Programs

HMS School for Children with Cerebral Palsy serves children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- **Physical & Occupational Therapies**
- **Special Education**
- **Speech/Language Therapy**
- **Music Therapy**
- **Communication Aids**
- **Special Medical Attention**
- **Adapted Recreational Activities**

Computer Technology
Communication Devices
Environmental Control
Powered Mobility

HMS, founded in 1882, is open to students two to 21 years. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy
4400 Baltimore Ave, Philadelphia, PA 19104
(215)222-2566

Circle #33 or visit www.eparent.com/adinfo

293

MARKETPLACE

BOOKS/VIDEO

Poetry Books about Autism
A mother's and poet's perspective;
"Seasons of Love, Seasons of Loss"
About diagnosis and discovery "Letting Go" on placing a son in a group home.
$7.00 for each book (includes S&H)
Mail orders to: Connie Post
P.O. Box 5591 Pleasanton, CA 94566
Checks to "Connie Post".
Get order forms at www.poetrypost.com

CHARITY AUTOMOBILE DONATIONS

Donate Your Vehicle
SPECIAL KIDS FUND
1-877-GIVETOK(IDS)
Call for information or donate online:
www.specialkidsfund.org

CYCLES

Cycles for Virtually Every Special Need & Age

Amputations, Cerebral Palsy, Spina Bifida, Visual Impairments/ Blindness, and many others

You Can Even Earn Your Own Cycle!
806-894-5700 FAX: 806-894-1238

Check us out on the Web...
http://www.rocknrollcycles.com

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

EDUCATIONAL MATERIALS

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

EQUIPMENT DEALERS

American
Discount Medical
Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg, PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider. Resource information:
www.medmarket.com
e-mail: info@archhp

Ask about our Youth Brief sample pack. Only $5.99!

HDIS **FREE CATALOG**

Call Today!
1-800-2MY-HOME™
(1-800-269-4663)

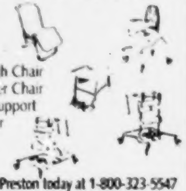
MONITORING SYSTEM

Care Electronics Inc.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price.
Call for FREE CATALOG

SEATING & POSITIONING

Designed With Children In Mind
Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Leckey products feature lighter mobile bases, more adjustable components, peer level positioning, child friendly positioning straps and playful colors.

- Freestander
- Totstander
- Easy Seat
- Advance Bath Chair
- Toilet/Shower Chair
- Basic Bath Support
- Pronestander



Call Sammons Preston today at 1-800-323-5547 for a complete Leckey® brochure.

RESOURCES

JACKIE--
The HeartWarming, Inspirational, True Story of a Remarkable Down Syndrome Girl
...Plus... Parables for Parents of Down Syndrome Children

As told by Jackie's Father, A Licensed Mental Health Professional
DAN JUNOT, LPC, CCHT

A must read for all family members, friends, clergy, family doctors, pediatricians, caseworkers, special education teachers, and other professionals associated with newborn and young mentally retarded children!

You'll love reading *JACKIE!* 110 entertaining pages of laugh-out-loud, cry-out-loud stories...with a point: practical, experience-based advice for nurturing the full potential of special children. You'll revisit *JACKIE* again and again as your child grows. Includes 4 pages of color photographs, that depict and accompany her real life adventures.

Order by Internet, Phone or Mail:
www.centerforspecialservices.com
1-800-510-5235 (24 Hours)
CSS, INC • PO BOX 804
THIBODAUX, LA 70301

$23.00
+$4.00
S&H

ASK FOR ITEM# 715EP

VAN CONVERSION DEALERS

MASSACHUSETTS

Motion Automotive Specialty
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—
Day, Week or Month.

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

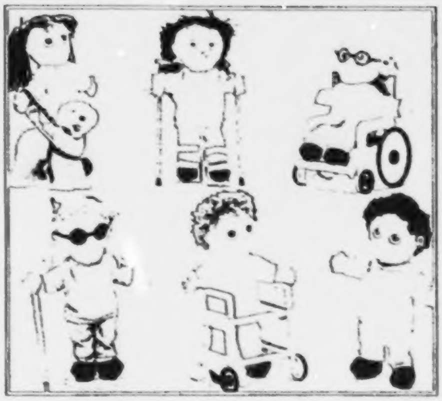
Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/ handling). To order, call 1-800-535-1910.

new products

SPECIAL NEEDS DOLLS

These dolls can be used as communication tools for clinicians, teachers and parents in order to initiate conversation with children. They are also great aids in helping children to adjust to, or better understand, their disabilities. They represent an array of disabilities, as well as cultural groups. These latex-free dolls are machine washable and appropriate for children ages 3 and up.

Sammons Preston, An Ability One Company, P.O. Box 5071,
Bolingbrook, IL 60440-5071; Phone: (800) 323-5547; Fax: (800) 547-4333;
E-mail: sp@sammonspreston.com; Web site: http://www.sammonspreston.com



DANCE BEAT DRUM™

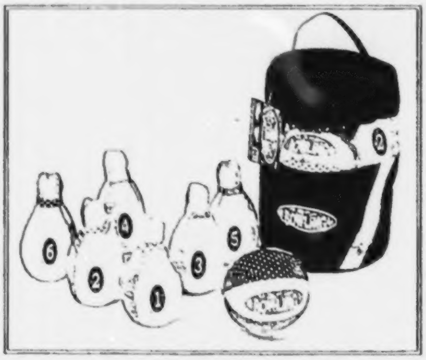
The Dance Beat Drum is a compact, colorful toy with red and white lights that flash. It features three brightly colored buttons with musical symbols that select three rhythmic modes. A fourth mode is activated by switching the setting to Melody. By stimulating sight, touch and hearing, it helps to improve a child's timing and reflexes. This interactive toy is for children ages 18 months and up.

TOMY Corporation, 4695 MacArthur Court, Ste. 130, Newport Beach, CA 92660;
Phone: (949) 955-1030; Fax: (949) 955-1037; Web Site: http://www.tomy.com

MOTHER'S 3RD ARM WITH A SWITCH

Mother's 3rd Arm with a Switch is an insulated foam holder that wraps around a removable switch. The switch is hidden in the cylinder of the arm and its long flexible neck adjusts in any direction for optimal positioning. The switch is activated by constant pressure.

Enabling Devices, Toys for Special Children, 385 Warburton Ave.,
Hastings-on-Hudson, NY 10706; Phone: (800) 832-8697;
E-mail: customer_support@enablingdevices.com; Web Site: http://www.enablingdevices.com



FUN GRIPPER BOWLING™

Fun Gripper Bowling can be used as an aid in developing perceptual, number and tossing skills for children ages 3 and up. The bowling set provides an easy-to-toss Gripper™ Bowling Ball, soft oversized numbered pins and a durable nylon carrying bag for storage and transport. The Fun Gripper Bowling Set comes in neon colors and can be used both indoors and outdoors.

Fun-Attic, 3719 Jasmine NE, Grand Rapids, MI 49525; Phone: (877) 293-5315,
(616) 559-3642; E-mail: sales@funattic.com; Web-Site: http://www.funattic.com

---

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

Differences Don't Count

by Jessica Mercola

I have brown hair.
She has blond hair.

I have long hair.
She has short hair.

I am chubby and short.
She is skinny and tall.

I have braces and glasses.
She has freckles and cerebral palsy.

I can draw, ride a bike and read.
She can't do any of these.

I can walk and sit.
She has a wheelchair,
and tries to talk
but out comes noises,
silly ones.

I like to draw.
She likes to go for long walks.

I am stubborn and loud.
She is sensitive and loving.

I am outgoing and fun.
She is different and interesting.

I go to dance.
She goes to therapy.

I drink from a cup and eat
regular food.
She drinks from a bottle and eats
pureed food.

I like to play outside.
She likes to play with noisy toys.

She doesn't make any choices.
We make them all for her.

I think I have a
good life.
Hers could be
better.

Every day I watch her grow,
in sorrow, laughter and snow.

I hope no one ever takes her away.
I would be lonely and miss her
every day.

I start every day with the positive
attitude that one day she'll be
just like me!

I don't care what we are.
I love her anyway.

I don't care what other people say.
We'll always be sisters and
the best of friends.
That's the way it's going to stay!

EP

MOM'S TURN

Julie A. Jasica-Mercola, Jessica's mom, says:
Jessica wrote this poem as part of a diversity contest at her middle school. While she wrote about a "she," the sibling in the poem is actually a "he," her younger brother, Jimmy. Jimmy is 6 years old; has hypotonic cerebral palsy and profound developmental delay; is non-verbal and non-ambulatory; and has the most gorgeous smile and eyes of anyone! Jessica also shares her home with her younger sister Rebecca, her father Bob and me. We are so proud of Jessica. She is incredibly compassionate, sensitive and hard working. Her poem won her an honorable mention at school and it has captured the eyes and hearts of her principal, our district coordinator for special needs children. She was able to show us, in simple words, the profound depth of her love and acceptance of the uniqueness Jim has brought to our family. She reminds us that, at the end of the day, we are all one of God's creations.

From left: Jimmy, Rebecca, Great Grandma Rose and Jessica.

Submit your Children's Page to: EP, Attn: Children's Page, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number, and e-mail address! ***Now on the Web!*** We will now be including **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

America's First Soymilk

Still the Best!

- Delicious nourishment in three flavors Original, Vanilla, and Carob
- Family farm organic GEO free soybeans
- Kid and earth friendly packaging
- Available in liter (33.8 fl oz) and single serving (8.45 fl oz) sizes
- Whole bean soy protein
- Cup for cup replacement in any recipe
- Visit www.edenfoods.com
  - over 200 free recipes
  - over 150 organic and kosher products
  - with nutritional information for each

For a free Quick & Easy 36 page recipe booklet with coupons call 888-424-EDEN or e-mail recipes@edenfoods.com

Eden Foods, Inc., Clinton, Michigan 49236

EDEN®

Ask for it at supermarkets everywhere.

ORIGINAL
EDENBLEND
CERTIFIED ORGANIC
Rice & Soy
BEVERAGE
EDEN 33.8 FL OZ (1.06 QT) 1 LITER
ORIGINAL
EDENSOY Light
TESTED GEO FREE
ORGANIC SOYMILK
Less than 1% Fat
Fortified with Vitamin D2 & Calcium
EDEN 33.8 FL OZ (1.06 QT) 1 LITER
parve
ORIGINAL
EDENSOY
ORGANIC SOYMILK
Nourishment from the Vegetable Kingdom
EDEN 33.8 FL OZ (1.06 QT) 1 LITER
with vitamin B-12
ORIGINAL
EDENSOY EXTRA
ORGANIC SOYMILK
Fortified with Beta Carotene, vitamins B-12, E, D, and Calcium
EDEN 33.8 FL OZ (1.06 QT) 1 LITER

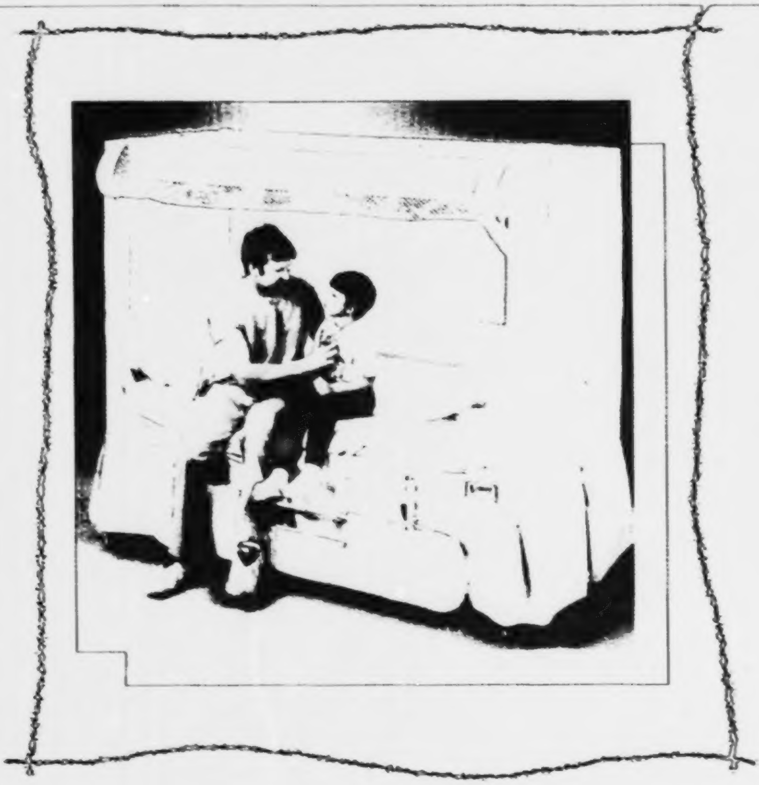
©2001 Eden Foods, Inc

Circle #26 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

A Better Bedtime Story

The Vail Enclosed Bed



Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for your child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt.
Plus, we provide assistance in obtaining insurance approval.

Available from home health-care products dealers, or direct from the manufacturer.

For a FREE catalog, call:
1-800-235-VAIL

BEST COPY AVAILABLE

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard

Vail Meadows Therapeutic Riding Center

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for
challenged riders.

Ask about Our Decorator Accessories.

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

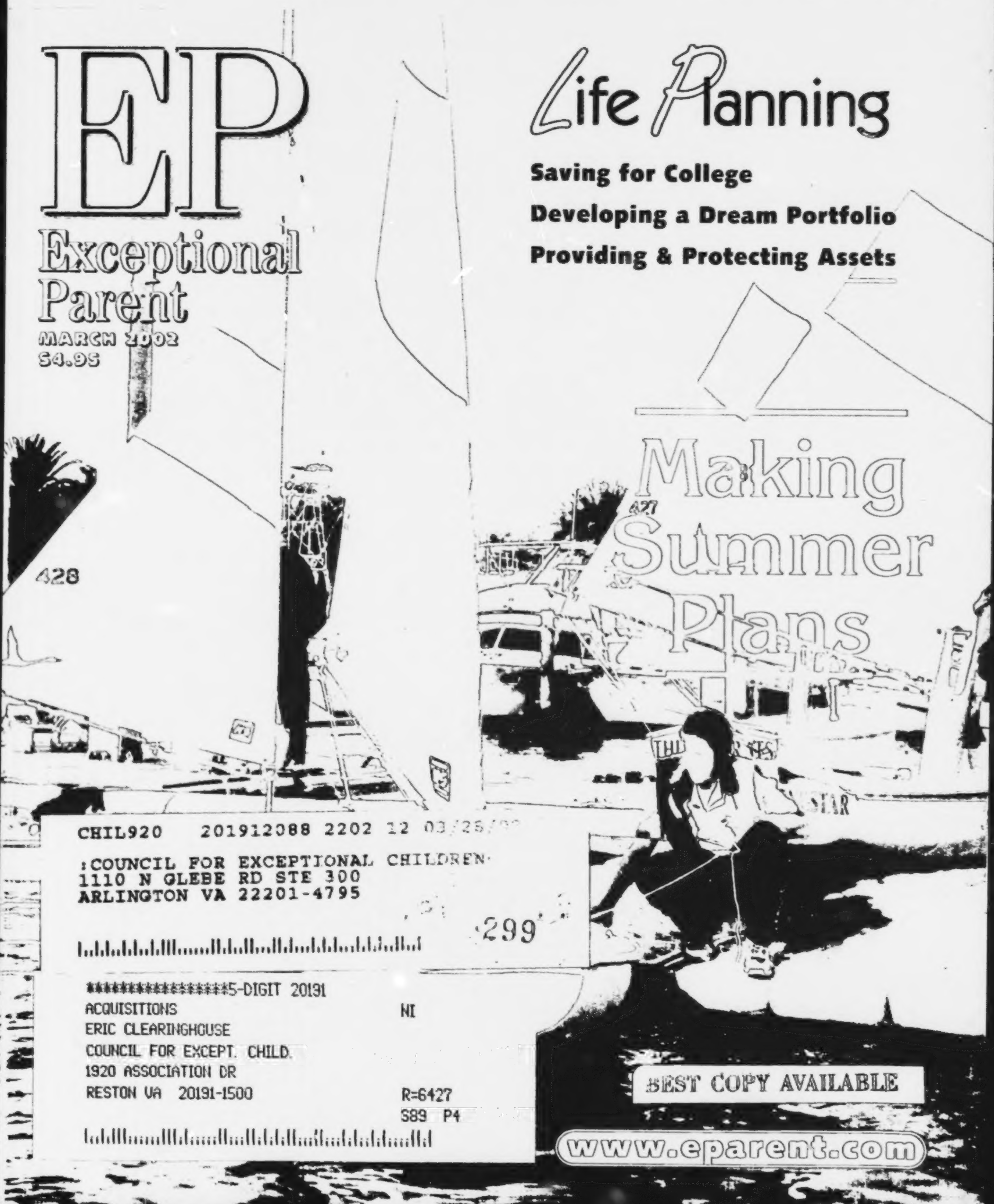
Sheri Wittmer
Sandusky, Ohio

Circle #56 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent

MARCH 2002
$4.95



Life Planning

Saving for College
Developing a Dream Portfolio
Providing & Protecting Assets

Making Summer Plans

CHIL920 201912088 2202 12 03/25/
:COUNCIL FOR EXCEPTIONAL CHILDREN
1110 N GLEBE RD STE 300
ARLINGTON VA 22201-4795
299

******************5-DIGIT 20191
ACQUISITIONS NI
ERIC CLEARINGHOUSE
COUNCIL FOR EXCEPT. CHILD.
1920 ASSOCIATION DR
RESTON VA 20191-1500 R=6427
S89 P4

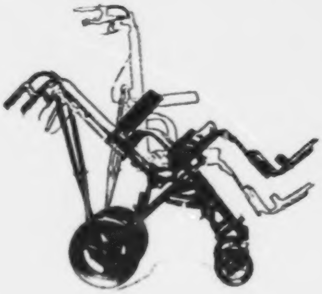
BEST COPY AVAILABLE

www.eparent.com

More Smiles

New & Improved

Safari Tilt



When you talk...
we listen

The new and improved
Safari chair is something
to smile about.

- New instructional video*
- Improved fold
- New style heel loops
- Optional recline,
  5 - 45 degrees
- Easy to tilt
- Crash tested

*Ask for free introductory video

Convaid

Circle #32 or visit www.eparent.com/adinfo

PO Box 4209, Palos Verdes, CA 90274 USA • Tel 1-888-CONVAID (266-8243) / FAX 310-618-8811 www.convaid.com

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

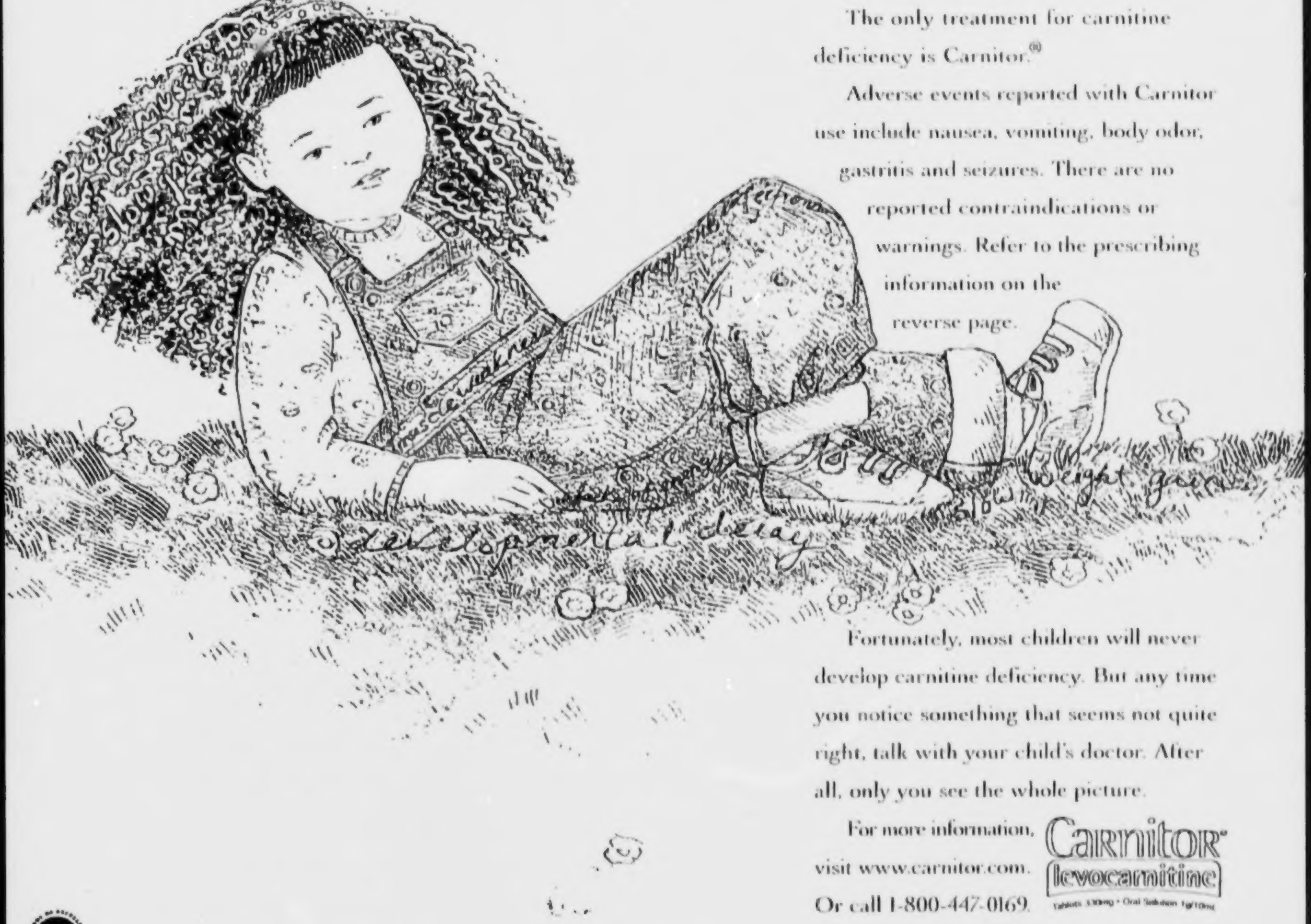
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Circle #67 or visit www.eparent.com/adinfo

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #79 or visit www.eparent.com/adinfo

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE
DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #54 or visit www.eparent.com/adinfo

contents

MARCH 2002 ◦ VOLUME 32, ISSUE 3

Life Planning

21 **Providing and Protecting Assets for a Loved One With a Disability**
by Robert M. Fink
The Georgia Community Trust is an example of a special needs trust.

25 **Saving for College With 529 Plans What You Need to Know**
by Timothy E. Lane
The benefits of a new tool in helping to pay for increasingly expensive college costs.

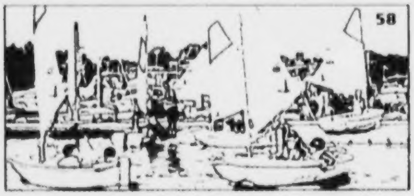
28 **Gina and the Group Home**
by Phyllis Donovan
The emotional decision-making process involved in placing your child in community living.

38 **Developing "My Dream Portfolio"**
by Shelly Weiss, EdS, LMHC, CRC, NCC
Young people with disabilities can plan for their future by carefully exploring their ideal life.

42 **The 5W's of Finding a Counselor**
by Audrey L. Canaff, PhD, NCC, LPC
How to choose the best counselor to meet your and/or your family's needs.

TRAVEL

58 **Shake-A-Leg Miami: Sailing for Everyone**
by Laurel Van Horn
Adapted ship ahoy! Special sailing program opens the seas for all.



59 **MEDICALLY SPEAKING What The Cruise Passenger Should Know**
by Linda Allen, MA, MCC
When setting sail with special needs, read this before booking passage.

52 **Camp C.A.M.P. A Unique Learning Experience**
by Larry McClaugherty, Lynn Vu, Tracy Virtue, Sherry Womack
Offering an experience to maximize potential for children with all disabilities.

FEATURES

46 **Research Reflections The Mystery of Family Research: Parents magically change from invisible to prominent**
by Jan Blacher, PhD
Changing views of the role of parents dealing with disability.

64 **Hyperbaric Oxygen Therapy In the Treatment of Brain Injury**
a Fact Sheet prepared by the United Cerebral Palsy Research & Educational Foundation

70 **PARENT PERSPECTIVE Sarah Syndrome: A Mother's View of Having a Child with No Diagnosis**
by Jennifer Frost
What's in a name? One parent points out that regardless of diagnosis, the challenges—and the love—are the same.

73 **ORGANIZATIONAL SPOTLIGHT CARES Foundation, Inc.**
by Kelly R. Leight
The CARES Foundation: information on congenital adrenal hyperplasia.

SPECIAL REPORT:

85 **Oral Healthcare for People with Special Needs Part IX—An Example of Full Inclusion Prevention of Oral Diseases** *by Christine Ernst Miller, RDH, MHS, MA*

89 **Sidebar: Make It a Healthy Smile: Finding what works for your child**
contributed by the HMS School

COVER: Set sail for adventure. These youngsters with disabilities at the adapted sailing program, Shake-A-Leg Miami, Miami , FL, are preparing to get under way with help from their instructor. See page 58 for the story. Photo by Laurel Van Horn, OPEN WORLD magazine

EP
Exceptional Parent

contents

DEPARTMENTS

10 Editor's Desk

14 Search & Respond

19 What's Happening
- Participants Wanted for Clinical Trial; Calendar of Events

20 Book Notes
- The Parent to Parent Handbook
- The Directory for Exceptional Children & Guide to Summer Camps and Summer Schools 2002/2003

72 Familiar Faces

77 Ask The Doctor
Focus on Pediatric Movement Disorders: Myoclonus
by Terence D. Sanger, MD, PhD
with Joy Bartnett, NASW, AMIA, AMWA

94 EP Library

96 New Products

100 Children's Page
The Only Difference
by Christa Forman

EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTH CARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy Ed Corp., dba *EXCEPTIONAL PARENT Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy Ed Corp. *EXCEPTIONAL PARENT®* is a registered trademark of the Psy-Ed Corp. **Postmaster:** Please send address changes to: *EXCEPTIONAL PARENT,* P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $64.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *EXCEPTIONAL PARENT,* P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *EXCEPTIONAL PARENT.* Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #1420542. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

EXCEPTIONAL PARENT neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
While hyperbaric oxygen is effective therapy in certain conditions it is currently considered an alternative therapy for CP and other "brain insult" conditions. Readers are advised to discuss the advisability of HBOT with their primary or specialty healthcare providers as well as to study the current literature.

—Rick Rader, MD

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

MITCHELL F. BRIN, MD, Vice President, Botox, Allergan, Irvine, CA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics , Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof. Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

HARILYN ROUSSO, ACSW, Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communication Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

THERESA VARNET, MSW, JD, Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

Informed Parents

Where Parents Keep Up To Date On Products For Their Children's Special Needs

Introducing
Danté
Alex

TIGER

Fun Fact

The Tiger can easily be placed on several different frames that allow for maximum versatility in and out of your home

Tiger Chair
On our indoor High-Low base, perfect for indoor activity

The Tiger 2000 is a unique and versatile push-chair that combines comfort with a beautiful design. Made for children up to approximately six years of age. The seat easily adjusts from an upright position to a horizontal position. This allows the child to be active or relax no matter where you go. The seat is also reversible allowing the caregiver to maintain eye contact with the child at all times. The unit folds easily for storage or transport.

Information/Free Catalog CD Rom
1-800-336-7684
snugseat.com

SNUG SEAT®

Circle #68 or visit www.eparent.com/adinfo

FIRSTFlex™
improving reach, grasp and pinch together.
Caring For Life

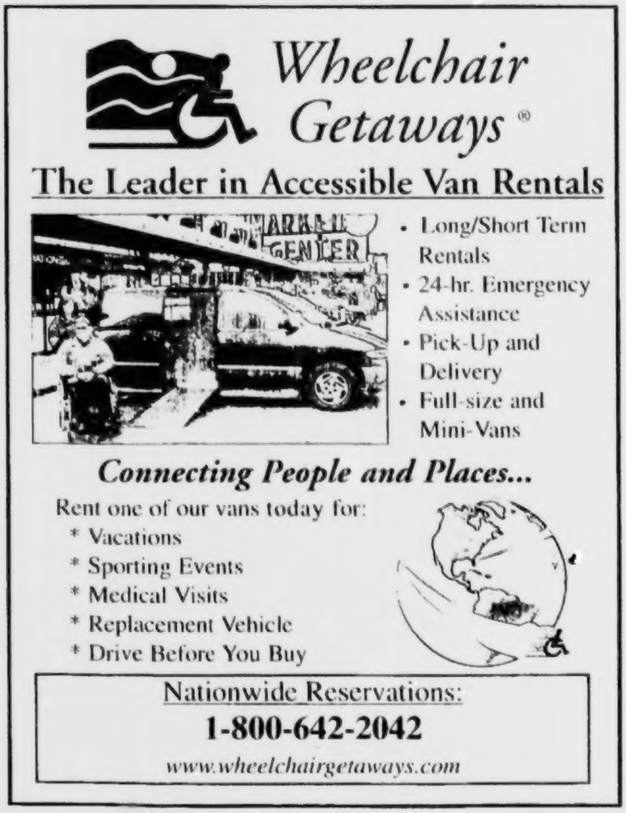
FIRSTFlex™, for children with spastic hemiplegia, combines patented bracing with electrical stimulation.

Before Treatment
Posture
Grasp
After Treatment
Posture
Grasp

www.ultraflexsystems.com

Call 1-800-220-6670 for free video and research studies.

Circle #77 or visit www.eparent.com/ad info



Wheelchair Getaways®

The Leader in Accessible Van Rentals

- Long/Short Term Rentals
- 24-hr. Emergency Assistance
- Pick-Up and Delivery
- Full-size and Mini-Vans

Connecting People and Places...

Rent one of our vans today for:
* Vacations
* Sporting Events
* Medical Visits
* Replacement Vehicle
* Drive Before You Buy

Nationwide Reservations:
1-800-642-2042
www.wheelchairgetaways.com

Circle #82 or visit www.eparent.com/adinfo

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

Editor-in-Chief	Rick Rader, MD
Managing Editor & VP of Medical Education	Fern R. Potvin
Editorial/Marketing Intern	Christina E. Spatz
Information Systems Coordinator	Dennis Dusevic
Research Assistant	Susan Jenkins
Graphic Consultant	Dennis Wilkes
President, CEO & Publisher	Joseph M. Valenzano, Jr.
Executive VP/General Manager & Associate Publisher	Robert S. D'Angelo
VP Business Development & Internet Projects	Vanessa B. Ira
VP Organization Relations & Consulting Editor	Bridget M. Lyne
Chief Financial Officer	Dolores A. Kinley
Ad Traffic Manager	Kendra Kelly
Sales Coordinator	Doris DeFina
Receptionist/Public Relations Coordinator	Robyn Sager
Art Direction, Design	Publishers Design Group, Inc. ✉annpdg@aol.com
Production Manager/ Trade Show & Conference Manager	Michael Longobardi
EP Library	Ron Richards (800) 535-1910 ✉eplibrary@aol.com
Webmaster	Ken Fleischer, Dynamic Media Works ✉webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Jared F. Adams
EASTERN REGION:
(CT, ME, NH, NJ, NY, RI, VT)
✉jadams@eparent.com
(201) 489-4111,
ext. 211
Fax: (201) 489-0074

Barbara Nastro
SOUTHEAST REGION:
(AL, AR, DC, DE, GA, FL, MD, MS, NC, PA, SC, VA, WV)
SCHOOLS, CAMPS, RESIDENCES & CLASSIFIED
✉ nastro@blast.net
(908) 534-6366
Fax: (908) 534-6941

Annabelle and Gabe Jacobson
MIDWEST REGION:
(IA, IL, IN, KS, KY, MI, MN, MO, NE, ND, OH, OK, SD, TN, WI)
AUTOMOTIVE
The Lyon Group
✉ bellyon@megsinet.net
(847) 256-6850
Fax: (847) 256-6819

Larry Battistello
WESTERN REGION:
(AK, AZ, CA, CO, HI, ID, LA, MT, NM, NV, OR, TX, UT, WA, WY)
Marketing Plus
✉ seeme4ads@aol.com
(760) 320-8797
Fax: (760) 320-9728

Vanessa B. Ira
MASSACHUSETTS & INTERNET AD SALES
✉ vieprnt@concentric.net
(201) 489-4111, ext. 209
Fax: (201) 489-0074

Jeffrey Yamaguchi
CANADA, AUSTRALIA, UNITED KINGDOM, & CUSTOM COMMUNICATIONS
ProMedia Communications, Inc.
✉ ProMedComm@aol.com
(905) 796-7931 ext 23
FAX: (905) 454-9671

Color Separation/Film Preparation
Plate Masters Inc., Carlstadt, NJ 07072

Publishing & Editorial Office
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

Subscriber Service:
Exceptional Parent
P.O. Box 2078, Marion, OH 43306-2178.

Customer Service/New Orders:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

Exceptional Parent magazine was founded in 1971 by Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 82

ORIGINAL
EDENSOY
EXTRA
ORGANIC SOYMI
Fortified with Beta Caro
vitamins B-12, E, D, and C
EDEN. (1.06 QT)
EDEN. SELECTED
MONTMORENCY
CHERRY JUICE
EDEN ORGANIC
Spaghetti Sauce
No Salt Added
EDEN. ORGANIC
Spinach Spirals
EDEN ORGANIC
KIDNEY BEANS
EDEN. ORGANIC
BAKED BEANS
Fat Free & Yummy
ORIGINAL
EDENSOY
EDEN ORGANIC
PINTO BEANS

Heart Healthy & Kid Safe

Eden offers food exceeding the requirements for the Food and Drug Administration's newest health claim for potassium rich foods that promote cardiovascular health. Prepared as if for our own children.

EDEN®

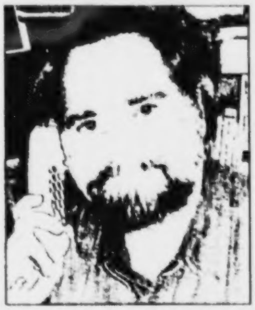
www.edenfoods.com

888-424-EDEN Clinton, Michigan

©2002 Eden Foods, Inc.

Circle #39 or visit www.eparent.com/adinfo

The Value of Observant Observation



When I was a medical student I was always amused when a professor began a story by saying "When I was a medical student…." Usually it was a clinical pearl that he or she had learned at the bedside under the tutelage of some great, memorable professor. Many times it was a reference to an era in which they didn't (couldn't) rely on MRIs, immunoassays or tandem mass spectrometry. "When I was a medical student, we didn't have quick access to thyroid hormone levels, so we would come back to the ward at about six p.m., take the patient's pulse, walk outside on the wrap-around porch and count the number of times the cricket "cricked" in a minute, divided them by two, and had a rough idea of the TSH. Of course it would only work in Burma."

So, to my amazement, I recently found myself starting a tutorial to students by saying, "When I was a medical student…" I guess it's one of the milestones of a physician's career, when what was learned as a medical student, viewed against the backdrop of the current reliance on technology, are "pearls" that are simply lost in the vortex of printouts. The subject was observing and observation—they are not necessarily one and the same—and their value in clinical decision making, not to mention their value in human interaction.

"Concern yourself with the man, lad, not the reports. Observe what's going on or maybe what's not going on here. Think about who's here and what he's all about."

"When I was a medical student," I began (wondering if I had to pay a royalty to the professors I learned it from at the North Middlesex Hospital in London where I trained), I had a professor who always emphasized the significance of observation. He liked to quote the aphorism of Dr. Thomas McCrae, "More is missed by not looking than by not knowing." So one day I was on rounds with this professor as we entered the room of a patient we had been following for about five days for a bleeding ulcer. My hands clenched the fresh reports, notes, lab results and other data I obtained by scurrying around the hospital before ward rounds to provide the professor with the updated clinical picture.

The patient was sound asleep when we entered his room and the professor stood silently at the foot of the bed. After a few minutes the professor turned to me and said "I think he's improving, what do you think?" I was clueless, and started to thumb through the reports to find evidence of "he's improving," because the sleeping patient certainly didn't offer any insight. "You're looking and not observing, Yank" he barked at me as the patient stirred. The professor turned to the patient and said softly, "Sorry to disturb you, Mr. Solomon, we were just remarking about your improved condition. How do you feel today?" Still groggy, the patient said that he was feeling better and that he had finally "paid a penny" the night before (an archaic English expression meaning that he moved his bowels). I found some lab data that indicated that indeed, his condition was improving. The professor turned to me and said, "Forget the labs. Tell me what clues there are to think the bloke's improving." I looked around and there was nothing outstanding that crossed my radar screen, nothing that announced that we should start thinking about discharging him. Actually, I wasn't even sure what I should be looking for; my training so far had emphasized collecting and interpreting clinical data like blood screens, scans that contrasted areas of tissues, fluids and air pockets and levels of every imaginable thing that could be leveled. "Concern yourself with the man, lad, not the reports. Observe what's going on or maybe what's not going on here. Think about who's here and what he's all about." I looked back at the professor with a blank look that I hadn't felt my face form since I was asked three weeks before by my neurology professor to describe the spinothalamic tract. It was enough of a time lapse that my face had almost forgotten how it felt. The face isn't the only thing that feels blank when you come up empty on ward rounds.

The professor turned to me and offered me the equivalent of "are there any final words you would like to say before we carry out the dictates of the tribunal?" Blank again, but with a left eye twitching to demonstrate that my face could do other things.

"I knew our patient was doing better since the last time we saw him yesterday morning because of what's going on here. Look at the table next to the bed. See the book on the table? The bookmark is at least two inches further down the book. Sick people don't read. He's doing better." The labs confirmed the advancing bookmark.

Only when we provide parents with a safe, encouraging milieu in which to share their observations, and we demonstrate our confidence and respect for these observations by following up on them, can we reap the benefits of "parents' eyes."

The professor was quick to point out that clinical decision-making should not be based solely on what you see, but your observations shouldn't be ignored, either. Surely medical advancements have propelled us beyond the significance of a patient's handshake, smell, fidgeting, uncombed hair or ketchup-stained tie….haven't they?

Perhaps no other discipline demands observation—intense, dedicated, purposeful observation—more than developmental disabilities. Clinicians, teachers, therapists, direct support professionals and parents need to look and look hard at people with special healthcare needs. They need to look with all they can see. As Professor Richard Schatzki (*Clinical Aphorisms from the Harvard Medical School*, 1957) hammered home to his students, "The eyes must finish their work before the gray cells take over."

As we've been stressing here at EP for more than 30 years, parents are our most keen observers. They need to be encouraged to share their observations with the rest of the healthcare and habilitation team. Only when we provide parents with a safe, encouraging milieu in which to share their observations, and we demonstrate our confidence and respect for these observations by following up on them, can we reap the benefits of "parents' eyes." Parents have trained themselves to look and think not only out of the box, but out of the clinic, out of the texts and, most important, out of the predictions. Clinicians and professionals should follow parents' lead and start looking for the bookmarks.

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

THE CENTER FOR CHILDREN • HOSPITAL FOR JOINT DISEASES

Caring for children with
Cerebral Palsy
requires the help of many specialists.

Now you can find them all at
one special place.

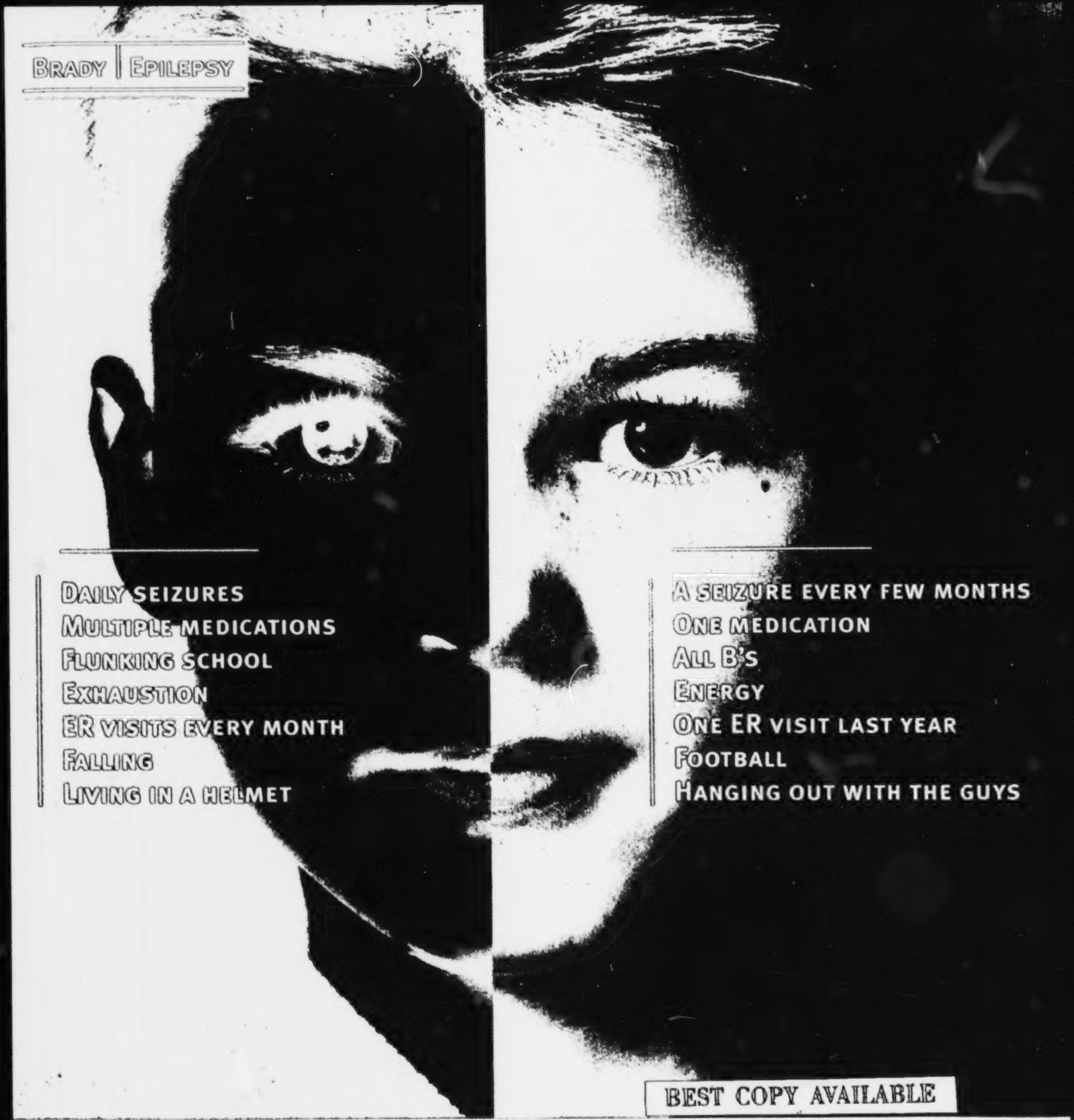
The Center for Children is the one place you'll find all the care options you need, with just one concern in mind: your child. By bringing together the resources of the Hospital for Joint Diseases (HJD) and the Rusk Institute of Rehabilitation Medicine (RIRM) of NYU Hospitals Center, we can care for a variety of conditions in one convenient setting. For example, you'll find the widest possible range of treatments for children with cerebral palsy, with in-house specialties including pediatric physiatry, orthopaedics, speech therapy, neurology, neurosurgery, physical and occupational therapy. All in a gentle, kid-friendly environment where there are no white coats, but plenty of color, interaction, toys, games and stimulation. From newborns to 21-year-olds, The Center for Children treats them better. **Call us at 212-598-2330.**

The Center for Children
Hospital for Joint Diseases
301 East 17th Street • New York, NY 10003 • www.jointdiseases.com

For additional comprehensive pediatric services, contact:
NYU Children's Health
866-CHILD-NYU

Mount Sinai NYU Health

Circle #75 or visit www.eparent.com/adinfo


BRADY | EPILEPSY
DAILY SEIZURES
MULTIPLE MEDICATIONS
FLUNKING SCHOOL
EXHAUSTION
ER VISITS EVERY MONTH
FALLING
LIVING IN A HELMET
A SEIZURE EVERY FEW MONTHS
ONE MEDICATION
ALL B'S
ENERGY
ONE ER VISIT LAST YEAR
FOOTBALL
HANGING OUT WITH THE GUYS

BEST COPY AVAILABLE

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

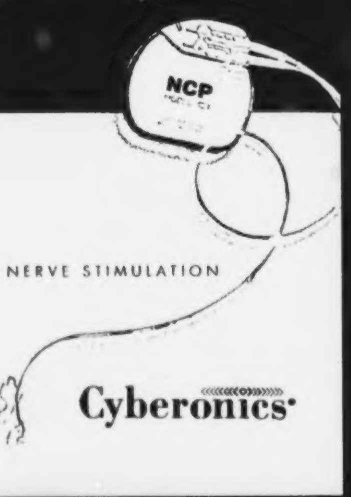
So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

BEST COPY AVAILABLE



VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS THERAPY

VAGUS NERVE STIMULATION

Cyberonics

Circle #37 or visit www.eparent.com/adinfo

Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our Web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Global developmental delay with no diagnosis

My son was born at 39 weeks, blue and not breathing, but with his heart beating. At one minute, he had an Apgar of 2, improving to an 8 at five minutes. For the first two months, he appeared fine until I found him in the crib blue, gasping for air, with blood coming from his mouth. Over the ensuing eight months this occurred eight more times. Despite admission to our Children's Hospital, the reason why this happened was never found.

Now at 3 ½ years of age, he has no speech, and has gross and fine motor delay. His genetic testing has come back normal, as have EEGs, MRI and CT scans. I am desperate as to what to do next. Anyone with any suggestions may e-mail me at roselli@shaw.ca.

Susan via EP web site

S

Galloway-Mowat syndrome

Our daughter, who is 7 years old, was diagnosed with Galloway-Mowat syndrome a couple of years ago. Also known as Microcephaly-Hiatal Hernia-Nephrotic syndrome this is a recessive, genetic disorder causing a variety of physical and developmental abnormalities including: infantile spasm seizures; central hypotonia; cortical visual impairment; microcephaly and kidney failure. She has just received a successful kidney transplant. She's never been genetically tested but she matches all the symptoms.

Our British Columbia Children's Hospital is unaware of any other children in North America who have it. Of course, now that we know she has a future we're interested in knowing about outcomes.

LT, B.C., Canada.

S

Need solution for behavior problems

My 7-year-old son suffered several strokes as an infant which left him with cerebral palsy and moderate to severe developmental delays in all areas. He has some speech, which is improving monthly.

Some of his behaviors, however, are becoming a problem at home and school. He likes to scream out and do heavy breathing. His neurologist says it's self-stimulation. I can ignore it sometimes, but these behaviors are real problems. The neurologist recommended Luvox, but it doesn't come in liquid and my son will not swallow a pill. We therefore started him on Paxil. A month later we see no difference in behaviors.

I don't know how to teach him to substitute a more appropriate behavior. While I realize there's no magic cure, I would be interested to know if others have experienced the same or similar behaviors with their child?

BHS via EP web site

S

Undiagnosed with heart defect, swallowing disorder, neurological issues

I have a 20-month-old daughter with severe delays. She has a heart defect (ventral and atrial septal defects), uncoordinated swallowing (fed via a gastrostomy tube), growth deficiency, short limbs, simian crease on right palm, reflux, and neurological issues (white matter volume loss and immature myelination) All chromosome tests and other tests have come back normal.

We are pregnant with our second child and would love to know more about our 20-month old. I would like to hear from parents with a child who has similar difficulties.

Amy, Columbus, OH

S

Holding a child back in school

My son has developmental delays in all areas—he is 7 years old and functions at the age of a 2- or 3-year-old. He attends public school and is mainstreamed in first grade. I was wondering if any parent out there had held their special needs child back in school.

I would like to know the advantages and disadvantages.

HB via EP web site

S

Motor skills deficit

My 5-year-old daughter is unable to perform simple motor skills such as writing with a pencil, sitting for long periods of time, or walking by herself for any extended amount of time. There is no medical term for it. She is completely on par with children her own age mentally and emotionally.

Does anyone know of any organizations that

I can reach out to for support in helping to find the appropriate schools or programs for her? Also, I'd just like an organization to help myself and my husband cope.

MS via EP Web site

Medication for high tone

My 4-year-old daughter had a near drowning accident shortly before her first birthday resulting in anoxic brain injury. She does not walk or talk, but is very alert and aware of her surroundings. Although her tone is extremely increased at times, her muscles and tendons do not reflect the amount of her posturing. I work very hard to keep her feet, legs, hands, and arms in good condition on the chance that soon she may be able to overcome her physical limitations.

I have debated for several years whether I should put her on medication to limit the amount of posturing she does. It has become increasingly frustrating to see my daughter making efforts to perform a voluntary movement and have the posturing completely disrupt her concentration. It seems that the more she makes an effort to try and do something, the more posturing she experiences. I would be interested in hearing from others who have any experience dealing with such severe posturing.

Shelley via EP web site

Congenital hypothyroidism and mental retardation

My daughter Elizabeth is 13 years old. She was born with congenital hypothyroidism and has been on thyroid hormone replacement medication since she was approximately 16 days old. She was off the medication for two years, from age 9 to 11. She matured physically very early, but has stopped growing in height. Her hands and feet are small in relation to the rest of her. We have been concerned about her lack of academic achievement for several years and now have been told that she is likely mildly retarded. I would like to know if anyone else has had this type of result even with early medication.

DG via EP web site

Instant S&R

Looking for summer solution

Our daughter has partial trisomy 13 which has resulted in a speech and motor delay and some developmental delay. Both my husband and I work full-time. Our daughter has spent her summers in a neighborhood daycare center since kindergarten, but this August she will turn 13 years old and will age out of the center. It would not be a healthy situation for her to stay home by herself all summer, as she is unable to speak (in an emergency) and wouldn't have the strength or agility in her hands to unlock the doors and get out if she needs to.

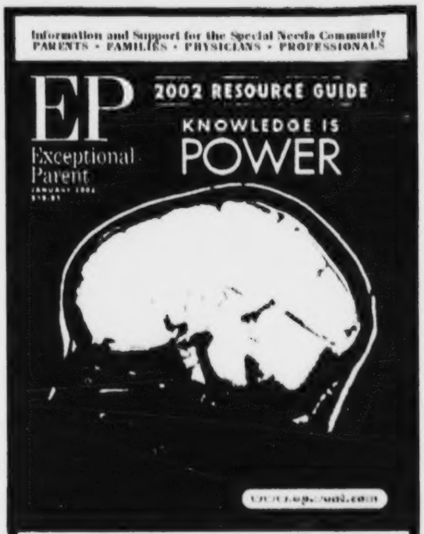
I am thinking of putting an advertisement in the nearby university newspaper for a companion, maybe a student of special education, who would stay with her on weekdays in the summer and on school holidays.

I would be interested in hearing what other parents in our situation have done or are doing for their adolescents with special needs. I would also be interested in hearing from college students who are studying special education as to whether or not this would be considered an attractive educational opportunity for a student.

LS via EP web site

Our 15 year old daughter, who has Smith-Magenis syndrome and chronic intestinal pseudo-obstruction, has had in-home caregiver-friends for the past five years. Her caregivers provide her with socialization, normal teen activities (malls, movies, etc.) and guide her through her activities of daily living and household chores. We have not had good luck with general newspaper ads but were very lucky at our local nursing school and by word of mouth. In order to make the job appealing, we always ask for more hours than we really need and are flexible with the number of hours. Sometimes this puts us above budget but the quality and consistency of care we have received has been wonderful. My daughter's life would be vacant indeed without the companionship of her "best friend."

Mary, MI, via EP web site


Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS
EP
Exceptional Parent
2002 RESOURCE GUIDE
KNOWLEDGE IS
POWER

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/handling). To order, call 1-800-535-1910.

HARD MANUFACTURING

AGE APPROPRIATE

BEDS

For when your child passes the crib stage!

Dianna Fitzgerald & Her Son Nicholas

Beds for children once they pass the crib stage are always an issue with parents. . . I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

The Stockton features full crib safety sides

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs, as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #47 or visit www.eparent.com/adinfo

EP

has the information an "Exceptional Parent" like you needs

EP Exceptional Parent

Your paid subscription includes the EXCEPTIONAL PARENT 2003 Annual Resource Guide, which normally sells nationally for $19.95.

This invaluable reference tool is a "must-have" for exceptional parents

Save $5.00 by ordering on-line at: www.eparent.com

For telephone orders call: 877-372-7368

Circle #199

Subscribe and be part of a network of "Exceptional Parents"

EP Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ______ Exp. Date ______

Name ______

Address ______

City ______ State ______ Zip ______

E-mail ______ Yes, I want more information to help me everyday.

Signature ______ E-mail ______

BMAR2

Subscribe and be part of a network of "Exceptional Parents"

EP Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ______ Exp. Date ______

Name ______

Address ______

City ______ State ______ Zip ______

E-mail ______ Yes, I want more information to help me everyday.

Signature ______ E-mail ______

BMAR2

Make someone a part of a network of "Exceptional Parents"

EP Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95

☐ 2 Years (24 issues) $65.95

☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year.

Other foreign countries $57.95 per year.

PLEASE SEND MY GIFT OF EP TO:

Name ______

Address ______

City ______

State ______ Zip ______

THIS GIFT IS FROM:

Name ______

Address ______

City ______

State ______ Zip ______

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ______

Exp. Date ______

Signature ______

Save more money: Order off the Web: www.eparent.com

XMAR2

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer life for themselves and for their children.

Exceptional Parent's MISSION

IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS
Don't miss a single issue:

SUBSCRIBE TODAY AND
RECEIVE THE 2003
RESOURCE GUIDE
GO ONLINE AND
SAVE EVEN MORE

EP
Exceptional
Parent

www.eparent.com

Participants Wanted for Clinical Trial for Young Adults with Down Syndrome

A large, US-based clinical trial of an investigational drug is currently underway and is recruiting young adults (18 to 35 years old) with Down syndrome to participate. The drug being studied is currently FDA approved for the treatment of mild to moderate dementia of the Alzheimer's type and is being studied in the Down syndrome population for potential improvements in attention, language, orientation, memory, and other areas.

Approximately 160 young adults (male and female) with Down syndrome are being sought to participate in the trial, which will take place in 16 clinical centers nationwide. The study is approximately sixteen weeks long (including screening). Participants and their caregiver/family member will be required to attend a total of four study visits over the study period. The subjects will receive daily oral medication or inactive placebo for 12 weeks and will have a 50/50 chance of receiving mediation or placebo during the study. At the end of the study, all participants will have the option of receiving active medication for an additional 12 weeks.

STUDY CRITERIA

Subjects must be:

- 18 to 35 years old and have a diagnosis of Down syndrome confirmed by karyotyping
- in general good health
- female subjects must not be pregnant
- able to swallow oral medication
- be English speaking
- without sensory or motor difficulties which could affect traveling to the site and completing study requirements (eyeglasses and hearing aids are permissible)
- without another psychiatric or neurologic diagnosis (e.g., major depressive disorder, schizophrenia)

Sixteen centers have been lined up for the study. If you know of someone who may be interested in participating, please contact one of the centers below for more information about the clinical trial. The evaluations and medication in this study are provided to participants at no cost.

Ann Guthery, Arizona Family Resource Counseling Center, Phoenix, AZ (602) 843-0000;
Holly DeFeo, Associated Neurologists, Danbury, CT (203) 792-6125, ext., 342;
Rena Tutus, Neurology Associates, Wilmington, DE (302) 656-2527 ext. 3033;
Adrian Verwayne, Atlanta Center for Medical Research, Atlanta, GA (404) 881-5800,
Katy Nichus, University of Iowa, Iowa City, IA (319) 356-8744;
Bee Pollock, Tulane University; New Orleans, LA (504) 587-3871;
Amy Heffner, Kennedy Krieger Children's Hospital, Baltimore, MD (410) 502-9622;
Julie Coleman, UAHC, Piscataway, NJ (732) 235-4907;
Jeff Swan, University of Rochester, NY (716) 275-8221;
Jennifer Sullivan, Duke University, Durham, NC (919) 681-1991.
Chris Heubi, Cincinnati Center for Developmental Disorders, Cincinnati, OH (513) 636-3881;
Annette Rulkowski, Metro Health System, Cleveland, OH (216) 778-3871;
Ralph Richter, Clinical Pharmaceutical Trials, Tulsa, OK (918) 743-4374,
Shelia Cannon, Children's Hospital of Pittsburgh, Pittsburgh, PA (412) 692-7963;
Sarah Damwood, Medical University of South Carolina, North Charleston, SC (843) 740-1592, ext. 13; and
Lorene Seman, University of Wisconsin, Madison, WI (608) 265-8244.

CALENDAR OF EVENTS

4/3-6 **CEC Annual Convention and Expo Hilton, New York Hotel, and the Sheraton New York Hotel and Towers, New York City**

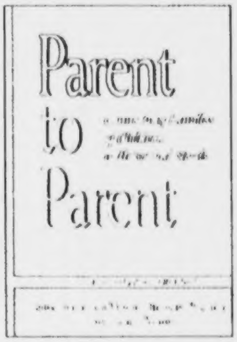
Professional development event (parents also welcome) for all who work with students with special learning needs. Conference includes over 600 sessions on current topics, lectures, panel discussions, mini-workshops, as well as exhibition of products and services. Full- or half-day preconvention workshops also available on topics including: behavior management and discipline, curriculum adaptation, assessment, transition, technology and more. For more information contact CEC Customer Service: (888) 232-7733 or CEC Web site:http://www.cec.sped.org.

4/5-7 **11th International Parent to Parent Conference, "In the Spirit of Sharing: Making the Connections," hosted by Parent to Parent of Pennsylvania in Philadelphia.**

Over 75 workshop sessions and several keynote addresses by parent leaders, individuals with disabilities, and professionals in the family and disability field. Formal and informal networking opportunities will be available throughout. Pre-conference day April 4 will feature sessions filled with strategies for starting and expanding a P to P program. For additional information contact Parent to Parent of PA at (717) 540-4722; Web site at http;//www.parenttoparent.org.

CORRECTION

The February article, "Dealing with a Parent's Worst Nightmare," contained an incomplete Web site for Jeanne Buesser and omitted her e-mail address and phone. They should be: http://www.community.nj.com/cc/apraxianetworkofbergencountyro Jbmistletoe@aol.com (201) 741-4035



The Parent to Parent Handbook

by Betsy Santelli,
Florene Stewart Poyadue
and Jane Leora Young
Published by Paul H. Brookes
Publishing Co., 2001
Available from the EP Library
(800) 535-1910
Code: PB4978GN
Cost: $29.95
plus shipping and handling.

For over 25 years, Parent to Parent (P to P) programs across the nation have been providing information and emotional support to parents who have a child, adolescent or adult family member with special needs by matching them with trained "veteran" parents who have already been there." *The Parent to Parent Handbook* is a detailed guide, not only on developing a P to P program, but as a primer for new parents who are entering an existing P to P Program. One who wishes to understand administrative, legal or organizational aspects of managing a non-profit group would also find this guide extremely helpful.

The guide is filled with first-hand accounts by parents who have been involved with a P to P program. These testimonials are laced throughout the text to elucidate almost every topic that is covered, allowing the reader to get a glimpse of how a real family who has a member with special needs handles various situations. Each chapter concludes with a summary and a list of all informational resources used in that chapter.

The book discusses the toughest topics first in the section, "Learning About Your Child's Disability." It covers discovering disability and dealing with emotional issues. In handling with the logistical side of the experience, the handbook discusses emotional and social needs of the entire family, financial needs, daily care, medical care and educational rights.

Part 2, expanding upon the discovery theme of Part 1, addresses the issue of finding support. Ideas and suggestions are listed which guide the reader toward finding his or her own support network.

The lion's share of the guide, contained in Part 3, "Starting and Developing a Parent to Parent Program," is dedicated to a basic yet thorough summary of P to P program development from matching parents to planning meetings to incorporating a leadership team. There is also a brief explanation of program funding, fund-raising, public relations or other fruitful organizational relationships. Sample templates, helpful in planning activities, charts, form letters, evaluation forms, sample bylaws and agendas are provided.

The guide concludes with Part 4: "Growing to the Future" and appendices detailing research on P to P programs, suggested readings and contact information. *(Ed. Note—See Calendar of Events for information on Parent to Parent's upcoming conference.)*

The Directory for Exceptional Children

Subtitled "A Listing of Educational and Training Facilities," the Directory contains over 2300 facilities in the US, private and public. The schools, clinics, and programs, both residential and day, are included free of charge and divided into sections for general special needs, including learning disabilities, emotional disturbances, autism, psychiatric and guidance clinics, orthopedic or neurological disabilities, mental retardation, blindness or visual impairments, deafness or hearing impairments, speech and language impairments.

Listings catalogue the facility's "vital statistics," such as contact information, conditions accepted, grades offered, academic orientation and curriculum, therapy and counseling offerings, enrollment, staffing, rates, financial aid, and a description paragraph. The Directory also has a section on disability-related associations and government agencies. In the back of the book are paid advertisements and an index that lists facilities in alphabetical order.

Guide to Summer Camps and Summer Schools

As part of more than 1000 listings, the Guide includes 113 "Special Needs Programs" for participants with behavioral disorders, brain injury, cancer, cardiac disorders, cerebral palsy, deafness, diabetes, dyslexia, emotional disorders, epilepsy, health/fitness, HIV/AIDS, learning disabilities, mental retardation, physical impairments, speech and language impairments, and visual impairments. As with the *Directory for Exceptional Children,* listings are free and include such information as costs, staffing curriculum, session length, age ranges and program description. Paid ads are in the back.

The Directory for Exceptional Children 14th Ed. 2001/02
Code: PS1412DI Cost: $75 (clothbound)

Guide to Summer Camps and Summer Schools 2002/2003
Code: PS1463DI Cost: $27 (paperback)
Both published by Porter Sargent Publishers, Inc.,
Available (plus S&H) from the EP Library (800) 535-1910

SUMMER CAMPS
SUMMER SCHOOLS

025 320

Providing and Protecting Assets

FOR A LOVED ONE WITH A DISABILITY

by Robert M. Fink

Government benefits are often a lifeline for people with disabilities and their families, but preserving eligibility while maintaining quality of life can be difficult. Many states across the country have addressed this problem by adopting legislation for community trusts. This article examines one state's solution, The Georgia Community Trust. (This article is not meant to provide financial investment advice.) —The Editors

The transfer of assets by gift or inheritance, although intended to benefit a loved one with a disability, can in fact be depleted by unnecessary expenses that would otherwise have been covered by public assistance programs. Generally, a person with a disability is entitled to receive both Supplemental Security Income (SSI) and Medicaid benefits. These public assistance benefits are based on the financial need of the person with the disability and are subject to income and asset limitations.

A person with a disability will lose public assistance eligibility if the total assets, after receiving a gift or inheritance, exceed the maximum allowable amount. Similarly, a judgment in a lawsuit for injury or a payment in settlement of a dispute would disqualify a person with a disability from receiving public assistance benefits, if the payment results in total assets exceeding the maximum allowable amount. Therefore, a person with a disability must then use these resources toward costs that would have been covered by SSI and Medicaid and will not qualify for SSI or Medicaid until the assets are depleted.

GEORGIA'S ANSWER

In 1996, the Georgia General Assembly passed and Governor Zell Miller signed into law the legislation making the Georgia Community Trust possible. The Georgia law basically adopted the federal law passed in 1993, OBRA (Omnibus Budget Reconciliation Act) which permitted pooled income trusts as special needs trusts. A trust is a separate legal entity created by a person (known as a donor) transferring assets to the trust. That person appoints a trustee who manages the assets. A pooled income trust is a large trust with many beneficiaries (a beneficiary is a person who benefits from the assets put in the trust). The funds are pooled for investment purposes, but a separate account is established for each beneficiary.

The law is intended to help Georgia citizens provide for the special needs of family members with a disability while preserving assets for the other members of the family. It is also intended to give a person with a disability an opportunity to provide for their own special needs. Under this law, a community trust must be sponsored by a nonprofit corporation, and trustees are required to have experience in business, finance, investment management, and providing services to people with disabilities. To be an eligible beneficiary of the Trust, a person must have a disability that substantially limits one or more major life activities, whether the impairment is congenital or acquired by accident, injury, age, or disease.

THE GEORGIA COMMUNITY TRUST

The Georgia Community Trust solves the dilemma of providing assets for a loved one with a disability. An individual can transfer assets to the Trust for the benefit of a loved one with a disability. A judgment or settlement payment can be made to the Georgia Community Trust for the benefit of the person with the disability. Through this arrangement, the person with the disability does not forfeit basic care he may receive through public assistance programs since the assets in the Trust are not considered assets of the beneficiary. The assets in the Trust can then be used to enrich the life of the person by covering expenses beyond those benefits provided by public assistance. The funds can be used for supplemental education, private rehabilitation, recreation, entertainment, medical and diagnostic treatment beyond Medicaid benefits, services of a direct support professional, and the purchase of furniture for the person with the disability.

The Georgia Community Trust, created in January 1998, currently has 40 beneficiaries and the total amount invested is approximately $2.2 million. It is the only community trust in the state, is sponsored by Ridgeview Institute, Inc., a non-profit behavioral health facility in Smyrna, Georgia. The National Mental Health Association of Georgia is a supporting sponsor organization.

HOW THE GEORGIA COMMUNITY TRUST HELPS FAMILIES

Bob is an 80-year-old widower with an estate worth $20,000. He has two adult sons, Robert and Richard. Robert, who has a developmental disability, has lived in a state institution for 40 years and receives both Medicaid and SSI benefits. Bob would like his estate to help Robert. But if he leaves his money directly to him, Robert will be forced to leave the state institution or will be charged for his care. Bob's $20,000 estate will be depleted quickly and Robert will have to go back on public assistance. Richard will inherit none of his

continued on page 22

CHILEDA INSTITUTE

Educators for youth with developmental disabilities. Residential treatment center provides complete training & intensive therapy for children with severe mental & physical disabilities, closed head injuries & challenging behaviors. Founded 1973.

- Intensive
- Progressive
- Specialized

founded in 1973

Chileda Institute
1020 Mississippi Street • La Crosse, WI 54601
608-782-6480 • Fax: 608-782-6482
Web site: www.chileda.org

Circle #29 or visit www.eparent.com/adinfo

Discover
New England Village, Inc.

"A community rich with opportunity, sharing and growth"

Established as a non-profit corporation in 1972, New England Village is a warm, caring stable and secure environment where young adults with mental retardation can lead a high quality lifestyle with opportunities for growth and friendship.

Our campus, set on 80 beautifully wooded acres just 25 miles south of Boston, offers attractive contemporary style homes and townhouse apartments. Learn about our full range of residential options, extensive vocational and education programs, and wide spectrum of recreation and social opportunities. We invite you to meet our dedicated and caring staff and speak to other families about our village.

Call (781) 293-5461, or write Judy Andracchio, Admissions Coordinator, to arrange your personal visit or request our brochure. We invite private and state-sponsored referrals.

New England Village, Inc.
664E School Street • Pembroke, MA 02359
781- 293-5461 • website: newenglandvillage.org
email: info@newenglandvillage.org

continued from page 21

father's money at either his father's or his brother's death.

The Georgia Community Trust offers Bob a new option. He can place all or part of his assets in the Trust to benefit Robert. Richard can serve as co-trustee to authorize expenditures for Robert's special needs. For example, the money could be used to enroll Robert in a woodshop class at a local community center and can pay for a trip to California to visit Richard and his family—including the cost of a direct care professional to accompany him. At Robert's death the assets in his Trust account will be transferred to Richard in accordance with Bob's wishes.

HOW THE TRUST HELPS A RECIPIENT OF A JUDGMENT

Jim is a 30-year-old man with a disability. He receives monthly SSI payments and Medicaid benefits. Jim is injured in an automobile accident caused by the driver of a truck. He engages an attorney and sues the owner of the truck for damages. A judgment is awarded to Jim in the amount of $20,000. When he receives the payment, he will forfeit his right to receive SSI and Medicaid benefits until his assets are reduced to $2,000. If, however, he transfers the funds from the judgment to the Georgia Community Trust for his own special needs, he will not lose his eligibility for public assistance.

COMMUNITY TRUST WITH INDIVIDUAL ACCOUNTS

The Georgia Community Trust is considered to be one trust fund for investment and management purposes. Individual beneficiaries of the fund have separate accounts to which net income is credited in proportion to each beneficiary's contribution. For example, assume that the trust has ten beneficiaries, each beneficiary receives 10 percent of the income from the Trust. These proportions change depending on expenditures allocated to individual beneficiaries. Assume that $10,000 has been contributed to each of the beneficiaries accounts for a total of $100,000 in the entire Trust. If $5,000 from her account in the Trust has been distributed to cover the needs of Sally, a beneficiary, her allocation percentage becomes 5.16% ($5,000/$95,000); the allocation for the other nine beneficiaries increases to 10.54% ($10,000/$95,000).

The Georgia Community Trust consists of two trusts:

- **Trust I:** The donor (the person who transfers funds into the trust) can select a trust fund based upon desired investment goals. The short-term goal of the Georgia Community Trust I is to keep funds available to meet the immediate needs of each beneficiary and the long-term goal is capital growth. To achieve the short-term goal, trustees invest in a quality money market fund that ensures ready cash. For capital growth, most of the Trust's assets will be invested in a taxable bond fund that provides a high level of current income from diversified portfolios of fixed-income investments. Funds will also be invested in an equity fund of domestic common stocks that pay dividends.
- **Trust II:** The short-term goal of the Georgia Community Trust II is to keep funds available to meet the immediate needs of each benefi-

ciary and the long-term goal is preservation of capital with some amount of growth. To achieve the short-term goal, trustees invest in a quality money market fund that ensures ready cash. For capital preservation with some amount of growth, most of the Trust's assets will be invested in certificates of deposit of national banks and US Government obligations.

APPOINTMENT OF A CO-TRUSTEE

Each donor creating a trust account appoints a co-trustee. The co-trustee, usually a family member, is the liaison between the Trust and the beneficiary who advocates for the beneficiary and requests funds to cover particular expenses.

FEES

Two fees are charged for establishing and maintaining a Trust account. The Initial Enrollment Fee is a one-time $300 fee paid by the person who will transfer assets to the Trust. A Consultation Fee of $400 is charged to cover consultation to the co-trustee. This fee is charged at the end of each calendar year (pro-rated for periods of less than twelve months) and is charged against each beneficiary's account.

PROTECTING A JUDGMENT OR SETTLEMENT PAYMENT

As was seen from the example of Jim, a judgment or settlement agreement may provide for payment to the Georgia Community Trust for the benefit of the person with the disability. The judgment or settlement may also designate a co-trustee and provide for payments to successor beneficiaries. Since the funds resulted from a lawsuit brought on behalf of the beneficiary, the funds will be considered to be donor-beneficiary funds.

SUCCESSOR BENEFICIARIES

When the donor transfers assets to the Georgia Community Trust, successor beneficiaries are designated. Upon the death of the person with the disability, the remaining balance in the account of the beneficiary will be distributed to the successor beneficiary.

DONOR-BENEFICIARY

If a donor designates himself or herself as the life beneficiary (the person who benefits from the trust during his or her lifetime), then the account of the life beneficiary is subject to certain limitations. In such case, the contribution to the Trust is irrevocable (cannot be taken out), and the donor or spouse cannot serve as co-trustee. If the donor-beneficiary designates a successor beneficiary other than the Trust, then upon his or her death, the account balance will be subject to repayment for medical assistance prior to the distribution to the successor beneficiary.

HOW EXPENSES ARE PAID FOR THE BENEFICIARY

A member of the Expenditure Committee of the Trustees will approve all requests to ensure that only expenditures permitted by

continued on page 24

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at **DISCOUNT PRICES!**

As a service to our customers, we offer **FREE SAMPLES** of disposable youth briefs and pull ups.

Save up to 50%
Call 1 800 777 1111 24Hrs
WOODBURY PRODUCTS, INC.
Order online at: **www.woodburyproducts.com**

GoodNites
GoodNites
GoodNites

Circle #83 or visit www.eparent.com/adinfo

est. 1978
Consumer Care™
Rehab Specialties Division

Special Purpose Products for Special Persons and Those Who Assist Them

See Our New & Expanded Catalog on Adults & Children

Quality Crafted
U.S.A.

VISIT Our Easy To Use & Fast Access Web Site
www.consumercareinc.com

- See & Learn about Products & 3M Supplies
- Obtain Dealer Referrals
- Positioning Management Programs
- Lease/Rental Options
- Trial Use/Evaluations
- News & Valuable Tips

Consumer Care Products Inc. Rehab Speciality Division
1446 Pilgrim Road, Plymouth, WI 53073, U.S.A.
Tel: 920-893-4614 or FAX: 920-893-6195
E-Mail: ccpi@consumercareinc.com

Circle #31 or visit www.eparent.com/adinfo

continued from page 23

the various public assistance programs are authorized by the Georgia Community Trust. Income and principal may be used only to provide non-cash benefits for special needs of the person with a disability beyond the basic support offered by Medicaid and SSI. When these requirements are met, the person with a disability retains his eligibility for public assistance.

MANAGEMENT OF THE TRUST

The Georgia Community Trust is managed by its board of trustees. The following individuals are trustees:

- ☐ Robert M. Fink, Founder and CEO of Ridgeview Institute; former partner of Troutman Sanders LLP, and former partner of Coopers & Lybrand.
- ☐ Ira E. Cavallo, President, The Georgia ARC/Network.
- ☐ Beth English, Executive Director, Southwest Georgia Easter Seal Society, Inc. and past president of The Georgia ARC/Network.
- ☐ Ruthann P. Lacey, Esq., Attorney specializing in elder law.
- ☐ Frank J. Murphy, President and CEO of the EP Foundation for Education, Inc., Atlanta, GA.
- ☐ George Olsen, Investment Vice President, R.W Baird, Atlanta, GA.
- ☐ David P. Pollan, Esq., Attorney specializing in elder law.
- ☐ Theresa Prestwood, Director of Development, Childkind.
- ☐ Cynthia A. Wainscott, Former Executive Director, National Mental Health Association of Georgia.
- ☐ Lynn M. Wilson, Chief Financial Officer, Ridgeview Institute.

GEORGIA RESIDENTS

At present, the individual transferring funds to the Georgia Community Trust for the benefit of a person with a disability must be a resident of the State of Georgia. There are similar trusts in other states and if you are interested in locating one of these trusts, please contact the National Mental Health Association or the ARC Network in your local area. EP

Robert M. Fink is the Executive Director of the Georgia Community Trust.

More information about the Georgia Community Trust is available from their Web site: http://www.georgiacommunitytrust.com or by contacting Robert M. Fink, Executive Director, (770) 431-7070 or via e-mail at: rfink@mindspring.com.

Changing Lives Forever

The Anne Carlsen Center for Children offers a 60-year tradition of residential, therapeutic and educational services on one campus. Our individualized services include care for children and young adults coping with cerebral palsy; orthopedic, vision and hearing impairments; autism, pervasive and other developmental disorders; and many other medical challenges. Our multidisciplinary team can reach out to you by conducting evaluations in your child's home and school setting.

Anne Carlsen
Center for Children
Changing lives forever

Jamestown, North Dakota
Call 1-800-568-5175 or visit our
web site at: annecenter.org

Circle #19 or visit www.eparent.com/adinfo

Saving for College With 529 Plans

WHAT YOU NEED TO KNOW

by Timothy E. Lane

According to 2001 Census Bureau data, the benefits of a college education are striking. People with a bachelor's degree earn 83 percent more, on average, than those with only a high school diploma. Over a lifetime, the gap in potential earnings is more than $1,000,000.

The harsh reality of rising costs, though, makes paying for college a formidable challenge for parents. The College Board's Trends in Student Aid 2001 reported that, for the 2001-2002 academic year, the average college cost at a four-year public institution was $3,754 (up 7.7 percent from 2000-2001), while the average cost at a four-year private college was $17,123 (up 5.5 percent). Furthermore, based on the latest expense figures from the College Board's report Trends in College Pricing 2001, parents of a child born last year can expect the average cost of a four-year college education to range by 2019 from $106,000 at public universities to more than $280,000 at private universities. Rising college costs, according to Trends in Student Aid 2001, are burdening more and more students with larger and larger loans. In fact, borrowed money now represents more than 60 percent of all financial aid, compared to 41 percent in 1980.

529 College Savings Plans Offer Help

Over the last five years states have been introducing what are known as 529 college savings programs, which can greatly assist families in saving for college. The programs are named after the section of the Internal Revenue Code which governs them. As a result of recent changes in the federal tax law, they now offer more attractive tax advantages and many plans now have more flexibility than previously. This makes them "a lot harder to resist," according to Business Week, January 28, 2002.

Tax Benefits

As of this year, the new federal tax law says that earnings on qualified withdrawals are to be free from federal income tax. While this federal-tax-free law is schedule to expire in 2010, most experts believe it will be extended. In addition to this federal-tax-free growth, earnings on qualified withdrawals may be either tax-deferred or tax-free on the state level; the benefit is obviously a much larger college nest egg.

But that's not all. Some states, including Idaho, Michigan, Mississippi, Missouri, New York and Oklahoma, offer state income tax deductions for a portion of plan contributions (these programs are managed by TIAA-CREF Tuition Financing, Inc.). The New York, Michigan, and Missouri plans were among Money Magazine's five recommended favorites (May 2001). The other two recommended by Money were Iowa and Utah, which both offer a tax deduction (these programs are managed by Vanguard).

Eligibility

Generally, there are no income limitations or age restrictions for account owners of 529 programs. And anyone can be named as a beneficiary—a child, grandchild, niece, nephew or, if the account owner is thinking about going back to college, the account owner. Account owners can transfer balances to siblings or certain other family members of the original beneficiary. So if one child decides not to go to college, a sibling, first cousin, or other relative can become the beneficiary of an account in the plan.

Contribution limits for 529s are considerably higher than the limits for other types of investments typically associated with funding higher education.

High Contribution Limits

Substantial amounts of money can be invested in most programs. In many, contributions can be made until account balances reach more than $200,000 per beneficiary, and there is no limit on the size to which accounts can grow through investment returns. Contribution limits for 529s are considerably higher than the limits for other types of investments typically associated with funding higher education.

continued on page 26

Positive lifestyles

for people with developmental disabilities.

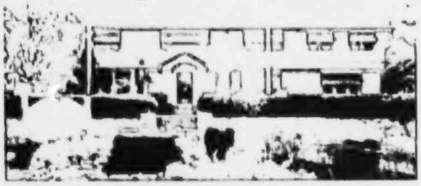
Residential, vocational and day programs are provided in a rural village setting. Residents enjoy community living, and a lifestyle designed to appreciate their individual characteristics. Respite care is also available.

Martha Lloyd

190 West Main • Troy, PA • www.marthalloyd.org • E-mail: mlcs@epix.net

(570) 297-2185, Ext. 268

Circle #57 or visit www.eparent.com/adinfo



Crystal Springs School

A PROGRAM OF THE

Institute for Developmental Diabilities, Inc.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeastern Massachusetts, close to Boston, Cape Cod, Providence and Newport, RI.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, Including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availablity.
- Licensed by the MA Office of Child Care Services.
- Approved by the MA Department of Education.
- Member of the MA Association of Approved Private Schools.

For information, Please Call Our Admissions Coordinator:

1-800-840-8087 (508) 644-3101 Ext: 375

Circle #36 or visit www.eparent.com/adinfo

continued from page 25

INVESTMENT OPTIONS

Many state 529 plans offer a managed allocation, age-based investment option, where assets are shifted from equities (stocks) to more conservative, fixed-income investments (often Treasury notes or high-quality bonds) as the beneficiary grows older. Key benefits of this investment option include professional asset allocation and fund management. Some states, in response to public demand, are offering broader choices. California's ScholarShare program, for example, has a 100 percent equity option, a Social Choice equity option and a guaranteed option to go along with its managed allocation option.

When choosing the investment options most appropriate for their needs, investors should consider many factors, including the age of the beneficiary, their own risk tolerance, and their overall financial situation. Higher equity allocations may appeal to those investors who are willing and able to take more investment risk and volatility for potentially higher returns over time, while a guaranteed option may appeal to those investors who are more concerned about preserving principal. Federal law allows investors to change the investment strategy for existing assets in a 529 plan account once per calendar year and/or upon a change in the designated beneficiary of the account. State programs may or may not allow this flexibility.

ELIGIBLE EXPENSES

Withdrawals may be used to pay for tuition, certain room and board expenses, required fees, and books, supplies and equipment, at nearly all colleges and universities in the US. They can also be used for vocational and technical schools, graduate school, and some foreign post-secondary educational institutions. If funds are withdrawn for purposes other than qualified higher education expenses of the beneficiary, the earnings are subject to federal income tax and an additional 10 percent penalty, and may also be subject to state tax and penalties.

ESTATE PLANNING

The programs also offer gift and estate tax benefits that can be significant. For instance, contributions are treated as completed gifts that qualify for the $11,000 annual federal gift-tax exclusion. In addition, an account owner, whether a parent, grandparent, or someone else, can deposit as much as $55,000 ($110,000 for a married couple filing jointly) as a gift in a single year without incurring gift tax consequences by simply taking the exclusion over five years (assuming the account owner makes no other gifts to the same beneficiary during this five-year period).

THE 529 EFFECT ON FINANCIAL AID

According to Trends in Student Aid 2001, nearly 60 percent of students currently enrolled in colleges and universities are receiving some financial aid, and more than 60 percent of all financial aid is in the form of loans. The remainder comes from grants and work-study programs. In determining federal financial aid, only 5.64 percent of parents' assets are taken into account; by contrast, 35 percent of a student's assets are considered. Given that savings in 529 plans are considered parental assets, the plans are clearly advantageous for financial aid eligibility compared to other college financing vehicles, such as Coverdell Savings Accounts (formally known as Education IRAs), pre-paid tuition plans of state universities, and custodial accounts; all these assets are considered to be the student's. When individual colleges decide on financial-aid packages for students, each institution decides how it will treat 529 assets.

Thus, despite what may have been said to the contrary, saving is prudent, even when it comes to receiving financial aid. Although saving in general may affect the amount of financial aid for which a student is eligible, generally loans will be affected. Loan money can't be considered true aid since the money has to be paid back — with interest.

DO YOUR HOMEWORK

When researching 529 programs, parents should understand their own child's likely educational needs; state-specific tax benefits, including any available deductions or matching contributions; management expenses and any other fees; and the investment track record of the program manager.

Investors are not limited to investing in their own state's plan, but rather can take advantage of nearly all plans. They may want to consider their own state's program first, though, particularly if it offers such advantages as state-tax-free growth and a state income tax deduction. Many states' plans are sold directly to the investor, with some featuring annual expense ratios below 1 percent. Other programs, however, are commission-sold by brokers, and thus may cost much more over the long term.

For information on any of the programs managed by TIAA-CREF Tuition Financing Inc., a subsidiary of Teachers Insurance and Annuity Association, call (888) 381-8283 or visit http://www.tiaa-cref.org/tuition. For information on any of the programs managed by Vanguard, call (800) 547-3332 or visit http://www.vanguard.com. For information on all states' plans, visit www.savingforcollege.com. EP

Timothy E. Lane is a Vice President of TIAA-CREF, where he manages the organization's Tuition Financing business.

Anderson School

Building A Tradition of Service for Over 78 Years

Anderson School provides the highest quality programs possible for children (ages 5-21) and adults with autism and other developmental disabilities. Anderson School is an educational residential community committed to an ongoing and fully integrated support network for their families and guardians. As an organization, Anderson School constantly strives to provide an enriched and positive climate filled with educational, cultural and recreational activities designed to foster continuous growth, independence and social interaction.

Located near historic Hyde Park (approximately 95 miles from midtown Manhattan) on a scenic 100 acre wooded estate overlooking the Hudson River, Anderson School serves all of New York State and welcomes out of state applications.

Now Accepting Referrals

- Residential and day students welcome
- Students accepted throughout the year

Call Kate Haas, Director of Admissions (845) 889-4034 Ext. 534
4885 Route 9, Box 367, Staatsburg, New York 12580-0367
www.andersonschool.org E-mail: mespie206@aol.com

Circle #18 or visit www.eparent.com/adinfo

Gina and the Group Home

by Phyllis Donovan

Gina is a beautiful little girl with chestnut brown hair and big fawn eyes. When she smiles, her cheeks puff up like over-stuffed raviolis and her eyes twinkle. On her good days she will come up to me and wrap her arms around my waist or put her velvety hand to my cheek. Gina has been diagnosed with autism/PDD; she has developmental disabilities and no longer speaks. Now that she is almost 10, Gina requires all my attention. She has the mind of a 3-year-old with some abilities of a 7-year-old and the strength of a 10-year-old. She is obviously capable of planning and logic; she has proven this many times with her antics.

> **You should know that this home will be the first of its kind in our county, so there will be much attention paid to the care that the children receive and to what goes on in the home.**

One morning in mid-1999, Gina's Service Coordinator and I sat at the kitchen table and talked about Gina. As I picked up my cup of coffee and began to take a sip, the Service Coordinator said, "I have exciting news. There is a group home that will be opening soon, sometime around January 1." I almost choked on my coffee and said, "Oh no, she's too young! We've considered this as a possibility for the future, but thought that she wouldn't go into any residence for at least eight to ten more years!"

"Well," she said, "Let me tell you what could happen." Should there be a crisis that includes the death of your husband, or you, or both of you, or an illness that is so serious that you can no longer care for Gina, then she could end up wherever there is an immediate placement available, or even in foster care. She could be placed 200 miles away! This home is about 10 miles away from here. The house has been purchased and now all that is left is renovation to accommodate the children. This is an opportunity for Gina and your family that you can't turn down. Since the house will not open for a few months yet, you have time to think about it. You can always change your mind, but if you don't put Gina's name on the list, the placement will be lost. You should know that this home will be the first of its kind in our county, so there will be much attention paid to the care that the children receive and to what goes on in the home. It is a major breakthrough for young people with developmental disabilities, and if Venture (the sponsoring agency) is going to create more homes of its kind, this must work for everyone involved. It will not be another Willowbrook, where the children are mistreated or neglected. You will be involved in everything from the start. You will be able to see the house and meet with the staff before the house even opens! You will not give up parental rights, guardianship is still yours, and the staff cannot even cut Gina's hair without your permission! You can visit any time you wish and take her home at any time for as long as you'd like. Children who have been in group homes like this one have eventually told their parents that they didn't want to go home some weekends because they would miss bowling or visits to the park. They love the activities and friendships they develop. And because she is no longer in your home, Gina will qualify for SSI and will receive a monthly allowance."

When my husband Frank came home from

work, I very carefully told him all the details that I could remember. Frank is a realist, and the thought of Gina being placed in a residence had been on his mind for a while. He knew that we couldn't wait much longer, since both of us were exhausted and worn out. We cannot turn our backs for more than a moment—and sometimes even that is too long. Every outing turned into a disaster. Gina would grab from other people's shopping carts, or run away from me if she saw something more interesting. She was an active, healthy child and I was aging much faster than my years. If we went to a park, it was hard to keep up with her. She was an excellent climber and we just couldn't scale those structures at the playground. Other times she would sit down at the top of the slide and not move for the longest time. Then there was the pain of seeing other people stare when Gina made noises or giggled non-stop. This was beginning to take its toll on us. Even though I didn't say it out loud, I knew that we would end up accepting the placement. Frank knew this too, and didn't hesitate to say so.

And so it began. Every time I thought of the placement, I would cry. We have three older girls: April, then 22; Laura, then 14; and Christine, who was 13. The very next morning they found me at the kitchen table, crying so hard that when they asked what was wrong I couldn't tell them. Each time I began to say it, I would sob.

I drove Christine to school and on the way managed to blubber a little bit out, enough for her to understand what I was saying. "No," she said. "Why do we have to do that?" But I didn't really have to tell her. After all, she lived in a house where all her nail polish was opened and painted on her clothes and on Gina's face, hands, clothes and shoes. She hid all her pens and pencils, only to have Gina find them and mark up her homework or pictures or books. Christine and Laura had no vacation time from school; they spent that time watching Gina while I worked part time. I got home from work at 3:30 p.m., so they couldn't go out until then. They couldn't stay out late the night before because they had to get up with Gina, who slept no more than 8 hours. I let Christine tell April and Laura since I knew that I couldn't tell them without sobbing again. My reactions were upsetting them, too, so I stopped talking about the placement until I could get a grip on myself.

They began to realize that they would have "normal" lives again, and that I would be calmer and able to renew old friendships or even make new friends.

Little by little Christine and Laura were leaning towards the group home for Gina. They began to realize that they would have "normal" lives again, and that I would be calmer and able to renew old friendships or even make new friends. April understood more than Christine and Laura. She had planned her wedding mostly without me, though she involved me when it was possible. Visiting the hall and tasting the cake were done during Gina's respite weekends. I spent my summer vacation running around for fittings and planning a last-minute bridal shower, and went back to work exhausted.

Venture, the organization opening the house, was good. Well known in this county, Venture was started by a woman who had a child with a disability born sometime around the late 1960s or early '70s. I had read her book about her son and the trials of raising a child with a disability without benefit of state aid. Although vague about the circumstances, I remember that at that time there was little help for this child and other children with disabilities. The woman had passed away two or three years before the home was started and one of her sons is now running Venture. The house was the first of its kind in the county and would be under close scrutiny. That made me feel a little more secure about Gina living there without us.

I have a friend in California who teaches children with autism, and I asked her about this home. She thought it would be extremely beneficial to Gina. I asked everyone I knew whom I thought might be helpful for their thoughts on group homes. I looked on the internet for a site about residences so that I could ask questions. I belong to two lists on the internet: both have members who are parents of children with autism/Asperger's syndrome, and I tossed the idea

continued on page 30

continued from page 29

around on one of the lists. To my dismay I received some very nasty emails, so I didn't post again about residences. Two friends on line helped me through some nasty moments, reminding me of the good this would do for my other children, my husband and me. They gave me positives when all I could think of were negatives. They were two of the best friends I could ever have. A friend of my sister was running a group home and I asked her many questions. I never stopped trying to learn what I could about group homes now that Gina would be entering one. That was October 1999, the home opened in October 2001.

All measures were being taken and additional renovation would be done to assure the safety of the children. We left the house a little more at ease.

When the purchase of the house was final, we went to visit. Other parents were there too, but most barely spoke. I suspect we were all feeling somewhat unsure and maybe even a little guilty about the venture we were about to undertake. Possibly these people had heard the same kind of negative comments as I. The CEO of the agency was there, the Service Coordinators were there, the heads of other agencies were there and some of the children were there. We went on a tour, saw the bedrooms and basement, and were told of renovation plans. The basement was still being renovated; padding and carpeting were to be added to ensure that the most active and mobile children could play there safely. All measures were being taken and additional renovation would be done to assure the safety of the children. We left the house a little more at ease.

Because of red tape and protests from the neighbors, the house would not open in January as planned. More meetings, and the budget approval was re-scheduled. To the shock of the agency, it was not approved. The house would not open in April—the proposed budget was too high. Venture had found someone familiar with the state budget approval process to help create a new budget. One problem was a staff nurse. Everyone wanted a nurse at the home, so cuts had to be made elsewhere. I agreed 100 percent that someone had to be there for the children at all times. Another quandary was the renovation. This too had to be approved and inspected, and apparently there were some glitches that needed to be corrected.

With each cancellation of the opening, I breathed a sigh of relief; although we knew it was coming and was necessary, at the same time I just wasn't ready to let go of my little girl.

When the school bus came in the mornings, Gina would giggle and run towards it. She loved school. I would watch her sit down in her seat. There was that little face looking out the window, with those two big eyes that didn't focus on me or seem to recognize me when the bus would return at 3:30 p.m. Those were the moments when I knew Gina needed more than I was able to give her. Those moments would strengthen my resolve about moving her into the Residence, as it was now being called. I was being torn in two different directions. I need her with me, but I needed time for the rest of my family.

A child needs her parents more than anyone else. Who can love her as much, or better? My motherly instincts were frightening me. I had to remind myself repeatedly that Gina warms up to people almost immediately, and that she would be fine. We would visit often and have her come home to visit. Gina needed 24-hour therapy and care, and she would get that living in the Residence.

I had been asked to write a little about Gina's day so the staff would know what she was used to. In order to make her adjustment easier, I wanted to write about her likes and dislikes, her food preferences and which foods she could not eat. I began writing in May and by July my piece about Gina had grown to five pages! I gave it to the Service Coordinator for the Residence staff.

July was our next tentative date. Our minds were now racing; we were caught in a storm of emotions. We wanted the time that this change would afford us but didn't want to say goodbye to Gina. Because she was non-verbal, I could not get any feedback from her. I told her about the house every chance I had, and about how she would be going out and doing things and have someone to care for her every minute of the day. I kept explaining it to her over and over, praying that she was getting the message. One day, while I was telling her of the activities she would participate in, she smiled at me. It was a tiny answer to all my prayers. She seemed to understand, and listened without any sign of sorrow. I had learned to read Gina's expressions and body language and felt comfortable with my instincts about her feelings. Just as I began to feel more secure about the move, though, I would remember that this was different, and I feared that my instincts were protecting me instead of Gina.

Just as I began to feel more secure about the move, though, I would remember that this was different, and I feared that my instincts were protecting me instead of Gina.

In early July we were invited to the house to sign papers and speak with the staff. We had arrived early so we toured the newly renovated house.

The front room was now a recreation room decorated in red, yellow and blue, and the walls were painted with figures from "The Lion King" and "Cinderella." Colorful buckets filled with toys were placed around the room, and a blue table and red chairs were set in the middle. "Pikachu" and "Blue's Clues" pillows adorned a glider in the corner. String, with colored clothespins to hold the drawings and schoolwork of the children, looped around the three connecting windows. An adorable pink bunny hung in the corner. It was beautiful, and welcoming to young children. Smoke alarms and sprinkler systems were in place in each room. The stone ledge of the fireplace this was covered in foam to protect the children from possible harm.

Then we went to see Gina's bedroom. The walls

continued on page 32

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

Coming Soon!

HYPERBARIC OXYGENATION FOR THE COMATOSE CHILD

There is some hope for the comatose child suffering from severe brain injuries, cerebral palsy, or anoxic encephalopathy. Children with Glasgow Coma scales from 3-5 present tremendous financial and emotional burdens, since these little ones may live for many years. When considering care of tracheotomy, gastric tube for feeding, physical therapy, occupational therapy, speech therapy, nursing care, recurrent hospitalizations, medications, vans, and modifications to the home, expenditures may represent multi-million dollars.

Intensive hyperbaric oxygenation is no miracle, but it provides some hope. In certain instances the child is able to communicate verbally, by computer or word board. Eighty percent have the G-tube removed and seventy percent have the tracheotomies closed. Frequently, bowels become normal and nutrition is re-established. Routine monthly medications are reduced and hospitalizations are markedly decreased. Although few children will return fully to society, substantial improvements will give them a better quality of life in addition to a ninety percent reduction in overall costs.

For more information on hyperbaric oxygenation therapy and life planning, call the Ocean Hyperbaric Neurologic Center at (800) 552-0255.

Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child..

by R. A. Neubauer, M.D.

Dr. Neubauer's new book is a complete guide written for the professional as well as the caregiver of exceptional children. The book describes the latest information on hyperbaric oxygenation therapy including improved brain function as visualized through functional imaging. Clinical and scientific data along with references are included.

Call 1-800-552-0255 to order

(800) 552-0255
• Call for free video & information

For more information visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #62 or visit www.eparent.com/adinfo

Hyperbaric Oxygen Therapy [HBOT] is the breathing of 100% oxygen under increased atmospheric pressure. The effects of HBOT on the organs and tissues of the body are multi faceted.*

South Florida Center for H.O.P.E. offers a clean and bright friendly atmosphere, using only state-of-the-art equipment. Our doctors and technicians are trained by a UHMS accredited course and certified in HBOT by the NBDHMT. They come with many years experience in the field of hyperbaric medicine.

* Hyperbaric Medicine Practice
Eric P. Kindwall, M.D.

WE OFFER H.O.P.E.
[HYPERBARIC OXYGEN PRODUCING ENVIRONMENT]

CONDITIONS TREATED WITH HBOT
- CEREBRAL PALSY [CP]
- TRAUMATIC BRAIN INJURY
- ANOXIC ISCHEMIC ENCEPHALOPATHY (AIE)
- NEAR DROWNING
- STROKE [CVA]
- MULTIPLE SCLEROSIS [MS]
- NON-HEALING WOUNDS*
- RADIATION INJURY*
- AUTISM

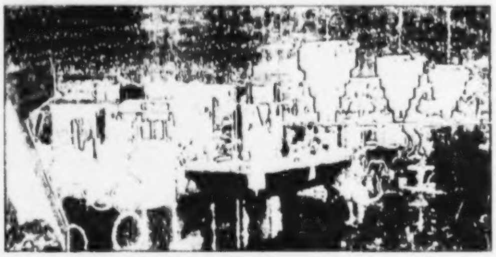
* CURRENTLY APPROVED BY FDA

ANCILLARY SERVICES
- INTEGRATED MANUAL THERAPY
- PHYSICAL THERAPY
- OCCUPATIONAL THERAPY
- SPEECH THERAPY
- BIO RESONANCE THERAPY
- NEURO-BIOFEEDBACK

South Florida Center for H.O.P.E.
1898 H West Hillsboro Blvd.
Deerfield Beach, FL 33442
[954] 571-9392
Toll Free: [866] 473-HOPE

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.
Circle #69 or visit www.eparent.com/adinfo

JUDGE ROTENBERG CENTER
A Special Education School for Children and Young Adults



- Serving children and adults with autism, behavior/psychiatric problems and other disabilities
- Highly consistent behavior modification with widest range of treatment procedures available
- Residential and education program
- Minimal use of psychotropic medication
- We accept the most difficult cases
- Employment opportunities available

Please see our web site, www.judgerc.org

240 Turnpike Street, Canton MA 02021
(781) 828-2202 Fax (781) 828-2804 www.judgerc.org

Circle #52 or visit www.eparent.com/adinfo

continued from page 31

were painted light lavender and, golden oak furniture had been partly stained a grass green. Over the windows were little picket fences with ivy woven around them. Curtains had been vetoed since Gina pulls on them. All aspects of the personalities of the children who would be living there were taken into consideration. Every thing matched and it was beautiful.

The dining room held two oak tables and that is where we gathered for our meeting. The staff congratulated me on the most extensive paper ever written by a parent about his/her child. I was embarrassed but felt the need to have these strangers know every little thing about Gina so that she would be understood and properly cared for. Ten years of parenting Gina gave me a unique perspective on her, and I didn't want anyone to misunderstand her wants or needs. The people running the house told me they were extremely pleased with my paper—I had left no stone unturned! I, in turn, was pleased that they all took notes when we spoke and were jotting down what I myself considered important information about Gina. We sat for about 45 minutes telling stories about Gina, answering questions from the nurse and other staff members, and then the meeting was over.

With the September 11 disaster preoccupying the Governor, papers had still not been signed, and the house could not open. This time it was understandable; but to my surprise, I was disappointed and disgusted.

Once again I felt a little more at ease. The staff would visit us at our house and we would sign a few more papers. I appreciated the way they watched Gina and listened intently when we spoke about her strengths and weaknesses.

This time it seemed possible that the home would open. I was scared and excited because by this time I was really exhausted. My schedule was tight and there was no time for anything other than Gina. The Service Coordinator took care of more legwork and paperwork so that Gina would be ready for the opening.

Around July 20 I received a call from the Service Coordinator telling me the home would not open. Although at the previous meeting we were told that "barring any major disaster" the house was ready, and although they had told us that the budget was approved, the check was still not in hand. We were more than a little confused; this was not the feeling I needed to have about the very people who would be responsible for Gina. They did not give me another date.

Laurie and Christine continued to watch Gina daily throughout the summer vacation, leaving to meet with friends only after I arrived home from work. They began taking turns with her so that they could have full days of vacation time, but she was getting to be too much for the girls.. I would come home to find that Gina had gotten hold of some nail polish, or a pencil, or opened the window and tossed out a block. Gina would run to me and grab my hand dragging me to get snacks and a drink, and would just cling to me.

School, and my rigorous morning routine, began again: up at 6 a.m., get myself together, get Gina up, get Gina fed and dressed, prepare my thermos, and get Gina's snack in her backpack. Go outside and wait for the bus, which came 10 minutes before I was due at work. Run to my car and race off to work.

With the September 11 disaster preoccupying the Governor, papers had still not been signed, and the house could not open. This time it was understandable; but to my surprise, I was disappointed and disgusted. This was my sign that it was "time."

Then I received another set of dates, October 27, 28 or 29, and was told to choose one of the three days. I didn't want to move Gina in on Sunday, because I needed a day at home to fall apart. I needed to adjust to the emptiness, the quiet that would permeate the house, so I chose Saturday. Frank works on Saturdays but this day he took off.

We really didn't believe it was going to happen; still, after being given hundreds of little name tags, I began the job of ironing them onto every piece of clothing she had, including socks, and even some doll dresses. I couldn't think about why I was doing this ironing; I was afraid. Frank didn't call his boss about Saturday, although he had warned him. He too just felt it wouldn't happen on schedule. By Thursday, we had no cancellation call and I began to realize that the Residence just might open on the scheduled date.

Saturday came and I was numb. By packing boxes the night

continued on page 34

Exceptional children deserve exceptional care.

The best help for cerebral palsy, spina bifida and related disorders is at Kennedy Krieger Institute.

For 61 years, Kennedy Krieger Institute has been the leader in helping children with severe disabilities. Focusing on early identification, intervention and treatment, our state-of-the-art interdisciplinary team approach—combined with a caring, supportive touch—has enabled generations of children to live their lives to the fullest.

Our comprehensive assessment and treatment for children with cerebral palsy, spina bifida and related disorders includes: Neurology, Medical Services, Nursing, Urology, Orthopedics, Physical Therapy, Occupational Therapy, Orthotist, Clinical Psychology, Neuro-Psychology, Seating, Feeding, as well as Rhizotomy, Spasticity and Movement Disorder clinics.

And unlike many programs, we see patients beyond age 18. Call Kennedy Krieger Institute today. We're here to help.

Kennedy Krieger Institute
707 North Broadway • Baltimore, MD 21205
www.kennedykrieger.org

1-888-554-2080
Kennedy Krieger Institute's Toll-Free Referral Line

Circle #53 or visit www.eparent.com/adinfo

continued from page 33

before, I kept myself too busy to think. We had breakfast and I stared at Gina even harder, watching her every move, trying to keep all those images inside my mind. I had been doing this since I was told of the home opening all those years back, but today was different. This was the day it would really happen.

We drove to the house in two cars, and when we arrived I was still pretty numb. We went inside and watched Gina run around playing in the rec room. We went into her bedroom to talk to the staff while they unpacked her clothes. They let Gina choose her bed and we laughed as she lay down on it, giggling. Gina took the hand of one of the aides and looked up at her with a little smile. We seemed to be in the way, since most parents had chosen Sunday as the day they would arrive and the staff still had much work to do. I was glad we had picked Saturday, because Gina would not have handled the chaos well. This way, she could acclimate herself to the staff and the house in peace. I finally turned to my family and said, "Maybe we should leave now?" I didn't feel any emotion and, I suppose now, I still wasn't accepting what was happening. The longer we stayed, the harder it would be for me to leave. Gina tried to go with the girls by taking their hands and heading for the door, and that upset them. I explained again to her that she would stay, and we would be back to visit.

Daily, I cried—for Gina, and for what I perceived as the terrible thing that I had done to her. It was getting harder and harder to deal with and I didn't know what to do.

Frank bolted and drove home alone. Christine was teary-eyed and Laura was quiet; there wasn't a sound in the car all the way home. April was waiting as we backed into the driveway. I looked over at Frank and saw him holding up Gina's cup; he had forgotten it and left it in the car. He was red-faced, and I burst into tears. Laura and Christine ran upstairs and ever-bubbly April chattered away, trying to cheer us as much as possible.

I didn't know what to do with myself. That day was the worst in my life. I sat at the kitchen table trying not to think but seeing images in my mind's eye, images of Gina watching her favorite Barney video or playing with her Lego blocks. All the good memories were there; none of the bad ones surfaced. This led to more feelings of guilt and remorse, more questioning of the decision to move Gina to the group home. I knew that we had the option of bringing her home, but I also knew that we would never have any kind of life if Gina were living here.

Every day after Gina moved, I got up, dressed and went to work. I would go to a store, and would see something that would remind me of Gina. I would think "What am I doing here?," then run out to the car and go home. This went on for at least a month. Daily, I cried—for Gina, and for what I perceived as the terrible thing that I had done to her. It was getting harder and harder to deal with and I didn't know what to do.

About a week after Gina moved to the Residence, I came home and looked around the yard: Gina's playground, pretty much the only world she had previously known. Her empty swing set and her trampoline. There was the little blow-up wading pool sitting under her swing just where she left it. I couldn't stand being on the deck where I used to put snacks and a drink for Gina after school. I remembered sitting and watching her play, as she would run from the swings to the trampoline. I had hung old CD's in the trees to scare the animals away from the garden, and when Gina discovered those flashing little orbs, she ran around giggling, and would swing them back and forth.

I thought, "Where is she? What is she doing now? Is she happy, sad, frightened?" I knew that I myself was feeling all of those things. Rather than stand there and fall apart, I grabbed a rake, and began raking the entire back yard. I raked for hours, yet the guilt was growing stronger and I raked on. I raked until I couldn't rake anymore, and realized it was dark. I went inside, exhausted, and started to cook supper. I noticed that a blister had grown and broken without my knowing it or feeling it. Episodes like this occurred sporadically. I would begin to feel sad, guilty, or frightened, and I would get up and clean until I couldn't clean anymore. I would mow the lawn, prune the bushes, deadhead the flowers—any job that required mindless hard work. I couldn't let myself think.

Then I went to visit Gina. It was only a week since she had moved to the Residence, but I missed her terribly. Just deciding to visit her made me feel happier. I went up to the house just after work, and waited at the window, excited that the bus would come and I would see Gina. She got off the school bus looking tired, and headed for the door. In my mind, I had blocked out Gina's autism and somehow fantasized that she would run to me, arms out, and fling herself at me. As Gina walked in the door the aide said, "Gina, look who's here!," but she barely responded. She was hungry—that was never the right time to get Gina's attention. The house was bustling now, with all the children coming in, and I was surprised at how quickly the noise and commotion died down. Gina came to me, and I hugged her.

The visit was a strange experience. I would look at the people at the Residence and know that they were Gina's caregivers now. I was just a visitor in this house. Whether this is true or not doesn't matter. My emotions totally controlled me, and my thoughts were jumbled. I realized that Gina was doing well. When I had to leave, she willingly went into the arms of another aide, and waved goodbye to me in her silly way. It broke my heart, because she wasn't acknowledging me as I had expected her to. I went home and had more crying jags. I thought to myself that I was acting stupid: Gina was happy, and that was what I wanted. I didn't understand myself anymore. All I ever wanted was to know that Gina wasn't frightened or felt deserted and now that I'd gotten my wish, I was still miserable. I seemed to be the only one in my family feeling this way. I realize now that this may not be true; Frank never asked me why I was so upset or why I was crying constantly, yet he seemed to understand.

The following Sunday, Frank could not take my crying anymore, so he picked up Gina and brought her home for a four-hour visit. I was in heaven, and enjoyed watching her play on her swings again. When it was time for her to go she didn't seem upset at all. Although I could not, and still cannot, bring her "home," Frank tells me she's happy when she gets there. Everyone greets her and she runs into the living room to sit and watch television. In retrospect I think that I was jealous of Gina's "new" family.

continued on page 36

"School" brings special challenges for a child with special needs

With over 40 years of assisting the child with special needs and his/her family we can offer:

- **Preschool Programs for the Child, age 3 to 5 with:**
  Mild to Profound Developmental Delays, Sensory and Communication Delays, and Hearing Impairments
- **School Program for the Child, age 3 to 21 with:**
  Multiple Developmental and/or Medical Needs including Acquired Brain Injury
- **We Offer All Students:**
  Small Classes with 210-day Caldenar
  On-site Nursing Services
  Assistive Technology
  Customized Adapted Equipment
  Augmentative Communication
- **We Offer All Families:** *(enrollment in school not necessary)*
  PT, OT, Speech/Language Therapy
  Comprehensive Audiological Services
  Family Support Resources (toy library, parent networking & referral, and more)

Call (203) 386-2743 for more information

FEROLETO Children's Development Ctr.
95 Merritt Blvd., Trumbull, CT 06611
www.stvincentsspecialneeds.org

St.Vincent's
Special Needs Services

Circle #71 or visit www.eparent.com/adinfo

I-EC

335

continued from page 35

Each time I visit Gina at the house it gets a little easier to leave without crying. I believe that she hadn't understood what I meant about her living there permanently, that maybe she thought that it was just another respite house. I see sorrow in her eyes, but I don't believe the sorrow is totally for her; I believe that she knows I'm sad about her leaving us. The staff takes her grocery shopping and feeds her on schedule, with snacks waiting as she arrives home. She is happy, although she misses us. She knows that she can't have the Residence, and all its activities, and us as well. Gina goes swimming weekly, to lunch at the local mall, to an indoor amusement park, the movies and the park, weather permitting. There isn't a weekend that some exciting trip isn't planned. We have Gina's visits scheduled so that she doesn't miss any of these trips.

I hope that someday I see the full benefit of Gina living at the Residence; it's only been three months. I do see changes in Gina, positive changes that make me feel, despite my sadness, as if we've done the right thing.

Now when we visit the house she runs to us. She is more aware, and signing on her own! Although it is minimal, she is signing on her own! She comes home happy, and yet when it's time to go back, she is not sad. She is mellow and solemn but not sad. I think that when I learn to accept this strange and unusual situation and stop being sad for myself, Gina will be happy.

Gina has a friend at the house now. Another child with autism, a little boy around Gina's age, follows her everywhere! Gina normally does not like anyone following her, but doesn't complain about this boy. On a recent visit Gina interacted with us much more. When I visit I always bring Christine with me. This time Christine had brought Pringles, for herself and to share with Gina. Gina put out her hand and Christine gave her a chip. Gina's friend Jerry put out his hand and Christine put a chip into his hand too. On the floor was a little child who has cerebral palsy and does not speak or walk. I was on the sofa so all I could see was Christine, Gina and Jerry. Suddenly a little hand shot up, palm out, Gina flicked her hand at his and the aide said, "Jack wants one too!" This was important, because I had never seen Gina acknowledge any of the other children until this moment.

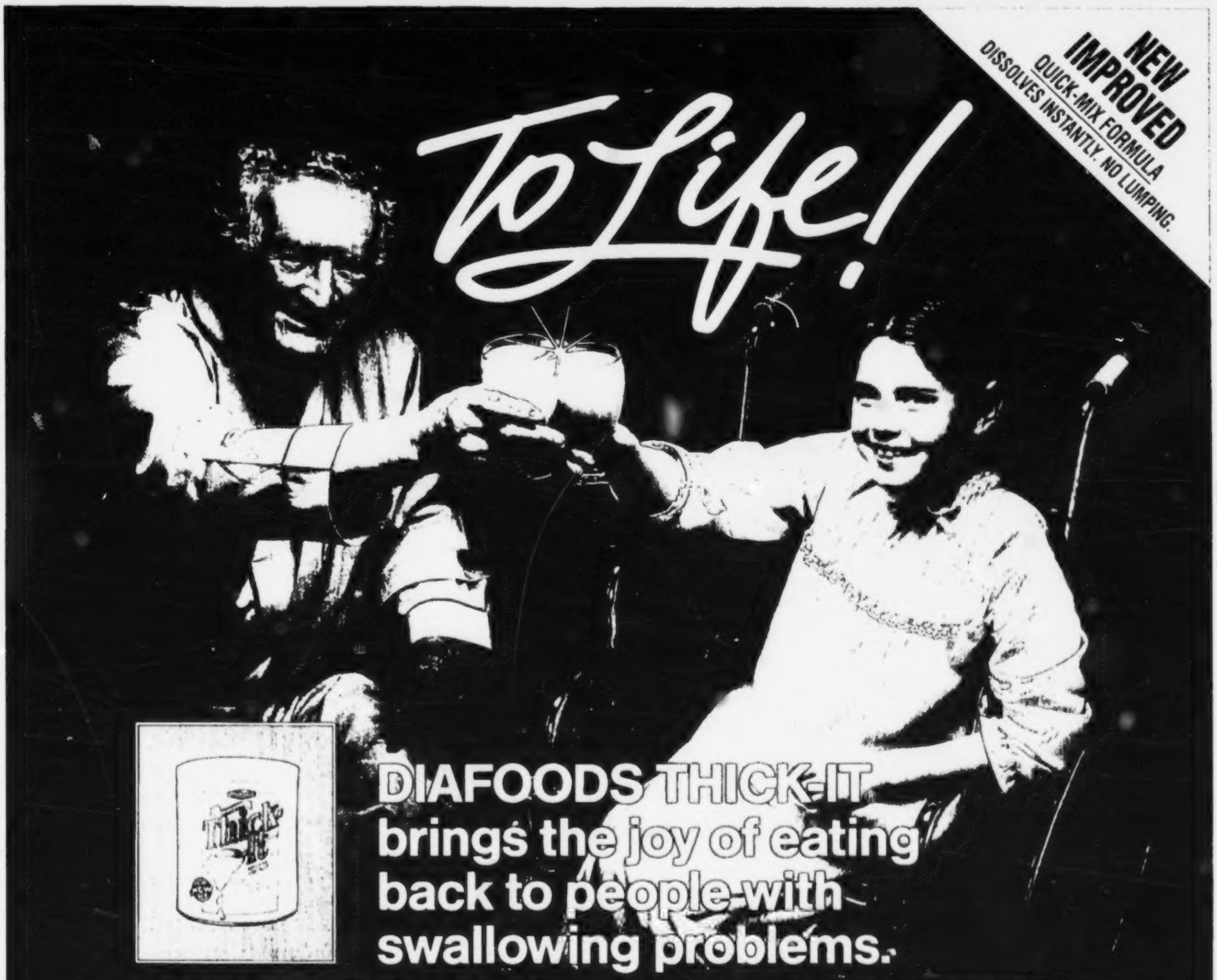
After the Pringles were gone Gina headed into another girl's room. This girl likes to watch videos and she had Disney songs on the VCR. Gina was enjoying the Disney songs—and the companionship of the girl! I watched as she rocked to the music and looked towards the other child. When I called out to her that she should come and visit with me, she waved bye and took me to the door!

I hope that someday I see the full benefit of Gina living at the Residence; it's only been three months. I do see changes in Gina, positive changes that make me feel, despite my sadness, as if we've done the right thing.

When Gina comes home now, there is no need to correct her or complain that she's taking over the living room. Everyone is happy to see her and patient with her. This is what we were no longer able to do with Gina when she still lived with us. Our fortitude was gone. The other family members, who also needed me, resented Gina's constant demands. I resented the lack of time to sit and relax. Gina now comes home and plays with her toys, watches television, and barely clings to me anymore. No more pulling me around because she's bored. She is so scheduled and active at the Residence that she appreciates just sitting here with us. We enjoy each other's company. During Gina's last visit I sang a little song to her as I used to do and she broke out in a huge smile, came to me and climbed onto my lap. Gina stayed on my lap and I continued singing until she got up.

Gina still comes up to me and puts her cheek against mine, or her lips to my cheek to kiss me. She touches my neck with her hand as she used to do, and I talk to her. She is not angry or hurt; she loves us. She's proven that she loves us, and knows us, and that is important to the entire extended family. EP

The Donovans live in the New York metropolitan area.



NEW IMPROVED
QUICK-MIX FORMULA
DISSOLVES INSTANTLY. NO LUMPING.

DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

For product literature and advice, a free sample and information where **DIAFOODS THICK-IT** may be purchased, **call... (800) 333-0003.**

Free educational material, call... (800) 333-0003.

The booklet **"Dysphagia, A Review For Health Professionals"** discusses causes, evaluation and treatment of dysphagia.

The pamphlet **"Swallowing Problems"** helps patients and caregivers understand and adapt to dysphagia.

©1996 PRECISION FOODS INC
2150 N. 15TH AVENUE
MELROSE PARK, IL 60160
TELEPHONE (708) 216-0704
FAX (708) 216-0709

BEST COPY AVAILABLE

Circle #64 or visit www.eparent.com/adinfo

Developing "My Dream Portfolio"

by Shelly Weiss, EdS, LMHC, CRC, NCC

Children with disabilities are routinely discouraged from developing their own self-determined quality of life. Expectations tend to be based on the individual's disability label instead of the individual herself. This has been evident to me in both my personal and professional experiences.

Because I was born with cerebral palsy, I have faced disability issues my entire life. While I was fortunate enough to be placed in regular classrooms and earn a standard diploma, for the most part my future was still decided for me based on my disability label. Not that I blame my parents, or the school system, or anybody else for that matter; on the contrary, without my support system I would not be the success I am today. Growing up in a small town, I was raised as an ordinary child instead of one with special needs. Therefore, deep in my heart I had the dreams and ambition of an ordinary child instead of a child with speech and physical impairments. Thanks to my faith in God, I was able to change my future, from the sheltered and safe lifestyle that most people with disabilities have to one that contained the values, interests, and goals of my self-determined quality of life.

> **The "My Dream Portfolio" process derived from the frustration I had experienced in seeing many people with disabilities settling for less in life, unaware of their limitless potential.**

SELF-DETERMINATION IN PURSUING DREAMS

My professional experience comes from my work as a certified rehabilitation counselor/licensed mental health counselor. I've worked with clients of all ages, disabilities, socio-economic statuses, and cognitive levels. Reflecting back the diversity of my interactions, I realize that no matter who I work with, there is one universal treatment goal: encourage clients to dream en route to the development of their self-determined quality of life. When individuals set their sights on something better—a self-fulfilling life—focus is taken away from the problem area and good things start to happen.

Hope and possibilities appear when children imagine the future that they would like to live. Ambition and confidence come alive. A dream composed of the child's self-determined quality of life is formed, including interests, values, skills, preferences and desires. Once that dream is formed (but not necessarily set in stone), excitement and determination become motivational factors for therapeutic process. Sometimes I think I must be missing something because it seems like such a simple process. Why isn't it being implemented everywhere? I've seen it work and have witnessed many wonderful success stories. By helping children create their dream life, I developed "My Dream Portfolio," a process which allows individuals (and family) to create their own options by encouraging children first to dream without limitations, then find ways to accomplish those dreams.

The "My Dream Portfolio" process derived from the frustration I had experienced in seeing many people with disabilities settling for less in life, unaware of their limitless potential. My frustration became most pronounced when I became a transition coordinator, helping high school students with disabilities prepare for post-school living. It sounded incredibly exciting yet simplistic to me. After all, spending most of my life in the "disability circle" of central Florida had given me an abundance of local contacts and resources. All I had to do was connect students with the appropriate resources needed to make their dreams come true. I was ready for the challenge!

The challenge was greater than I had anticipated. When I asked these high school kids what they would like to do after high school, I got blank stares, shrugged shoulders, and responses such as, "let me ask my mom and tell you tomorrow." Even after emphasizing that I wanted to know *their* dreams for *their* lives, most of the 60 or so students could not give me an honest answer.

No one had ever asked them about their dreams before, at least not in a serious manner. Working with these students reminded me that instead of being viewed as individuals with their own set of needs, values, preferences, skills, etc., children with disabilities too often are seen solely in the light of their disabling label. Consequently, these kids automatically inherit expectations and limitations based on the perceptions and/or knowledge of the dis-

continued on page 40

Sharing the Caring

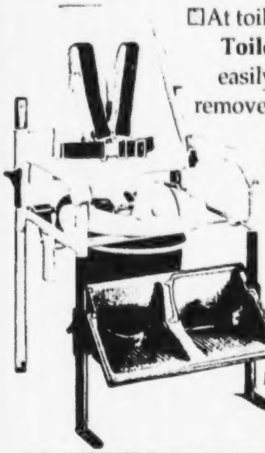
Sally, 40 lbs. and 45" tall, in the #8600 Reclining Bath Chair with #8875 Head Pad

BEST COPY AVAILABLE

Columbia offers you solutions to the daily challenges of bathing, toileting and transporting your child – *with comfort, safety and ease!*

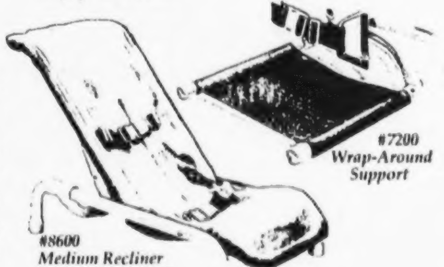
You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

☐ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.



#5800 Hi-Back Positioning Commode for junior adults

☐ At bathtime, our popular **Wrap-Around Bath Supports** and **Reclining Chairs** allow your child – and you – to enjoy the bath.



#7200 Wrap-Around Support

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

☐ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.–yet weighs only 11 pounds! Comfort, style and adjustability have made it the No. 1 choice since 1986.

#2000 Car Seat

Why do these products work so well?
Much thought and care go into the design of each Columbia product. We make each item in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, proven in real life. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

COLUMBIA
SHARING THE CARING

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG
Columbia Medical Mfg. Corp., Dept D2, P.O. Box 633, Pacific Palisades, CA 90272
Visit our web site at http://www.ColumbiaMedical.com

Circle #30 or visit www.eparent.com/adinfo

continued from page 38

ability from people involved in their lives. As a result, they go through life believing their options are limited.

LOOKING AT ALL THE OPTIONS

I make it a rule when facilitating "My Dream Portfolio" never to tell someone that his or her dream is unrealistic. By discouraging the exploration of the child's ideal life, no matter how impossible it seems, I would miss the chance to learn what truly matters to the child. One of my favorite examples of this is my student who wanted to be an astronaut. Since he was on a special diploma and not "college material" (according to his teachers), he was ridiculed whenever he'd share this dream. However, when he trusted me enough to share his ambition with me, I asked him to describe what his life would be like as an astronaut. His eyes lit up and with a face full of excitement, he replied, "Well, I get to wear this bubble helmet." When I encouraged him to go on with his description, he continued describing the space helmet.

This student had no idea what being an astronaut entailed; all that he knew about the profession was what he saw on television. After further discussion, he revealed that a major part of his quality of life was being able to wear a bubble helmet. When we discussed it, we came up with the idea that working in a costume shop where he could wear such a helmet at his leisure would be his dream job. Without exploring his so called, "unrealistic" dream, we would never have discovered what was important to him.

Often, we set goals only to change or modify them as we gather new information and experiences. If I had not pursued my dream of being a clinical psychologist, I never would have found my niche of rehabilitation counseling. I remember being 8 years old and dreaming about being a psychologist specializing in disability adjustment issues. Of course, since I have slurred speech and wasn't considered college material, my dream was almost as unrealistic as the one of employing Tom Selleck as my personal secretary! Yet I ended up pursuing my dream, even after finding out that only a handful of students per year are accepted into the clinical psychology program. It wasn't until my final year of undergraduate studies that I learned of rehabilitation counseling; not only was admission to the program much more likely, but the job description was exactly what I had always dreamed of doing. As far as my speech impediment was concerned,it has turned out to be an asset, for the most part, because I can relate to what my clients are going through.

For this reason, I encourage children to dream and share as many details of the dream as possible. There's an old saying, "I'll believe it when I see it." Well, "My Dream Portfolio" embraces the opposite as a basic premise: "I'll see it when I believe it." If the individual is not able to imagine the dream, how is she supposed to implement the dream? Having the child describe it shows me the child's perception of a goal, whether it is a job, living independently, marriage, or any other life goal.

SETTING NO LIMITS

"My Dream Portfolio" also helps the individual view the consistency of his goals in the context of an ideal day-to-day life. For example, students who plan to work at a minimum-wage job, yet want to drive a sports car and live in a mansion, are shown basic budgeting skills. I give them a brief lesson on the value of money in order to help them understand the importance of setting priorities. There's no reason why someone with a minimum wage job cannot buy a sports car as long as the car payment and insurance are the only bills he has. The same concept is used with students who hate school, yet want to go to college. Instead of telling them they cannot pursue their dream, I show them a 250-page textbook, explaining they'll be required to read one of these per week. They decide whether their dream is worth the effort, or if they prefer to find alternatives.

Frequently, I hear parents tell me that "My Dream Portfolio" would not work with their child because of the severity of limitations, yet I have not met anyone who could not benefit from the process. To prove its adaptability, I have used my cat, Zoey, as an example. I know what makes her happy, what she's good at, and what an "ideal" day would consist of for her; her quality of life is made up of lots of nap time, playing with her brother, Seminole, and a limitless supply of wet cat food. That would make her happy.

> **"My Dream Portfolio" also helps the individual view the consistency of his goals in the context of an ideal day-to-day life.**

Children with disabilities deserve to have input into their future. While the amount of input will vary from child to child, so will the components of their quality of life. The best way to learn about the child's dream is to get to know the child. **EP**

Shelly Weiss EdS, LMHC, CRC, NCC, is a professional therapist and disability awareness consultant in private practice. For more information, contact her Web site at www.umbrellasanddolphins.com.

340

Who will care for your disabled child when you are gone?

**Litigators Incorporated, P.C.
& Affiliated Law Firms**

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

**Check out my web-site at
www.thelitigatorsinc.com**

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #55 or visit www.eparent.com/adinfo

The 5W's of Finding A Counselor

by Audrey L. Canaff, PhD, NCC, LPC

From time to time, families of children with special needs may decide to seek professional counseling to assist them with the problems of everyday living. Counseling can be a mysterious process. Often practitioners in the field disagree on what counseling is, who should be doing it, and what process or processes unfold in the counseling relationship. As a counselor educator, I am charged with teaching counselors in training who may come into the field with their own assumptions and misconceptions. Part of their journey toward becoming a counselor is learning to articulate their own definition of ways of working with and helping individuals. If the process seems vague to counselors in training, imagine what it feels like for a person seeking counseling.

As a way of clarifying the enigma of the counseling field, let's look at the "5 Ws" of counseling; the why, when, who, where and what.

WHY AND WHEN

Families of children with special needs face challenges from a number of fronts and may feel stress from various sources. These can include spouses, family members and the community at large. Some specific scenarios that families with children who have special needs may find themselves in warrant counseling.

Family systems theory is the belief that all members of a family unit are interconnected and dependent on one another. Any change in one member will affect other members. The presence of a child with special needs will affect other siblings within the family unit. Counseling may be needed when siblings begin to have school difficulties, interpersonal problems or express jealousy and anger toward their sibling. In the same vein, marriages may suffer, as the focus of the family may lie in the care, support and advocacy needed for the child with special needs.

Families often experience isolation from the community. Children with special needs may not be included in playgroups, birthday parties and many of the childhood rituals that unite parents in a community. The lack of knowledge about the child's condition and discomfort experienced by some will increase the sense of loneliness and alienation. In addition, the family of a child with special needs expends a great deal advocating for the appropriate medical care, education and socialization necessary for their child's quality of life. This constant up-hill battle can produce stress and burnout. The lack of support from both the smaller community and society at large can result in feelings of sadness, isolation and anger. Counseling can provide a support system to help caregivers with these emotions.

A multitude of emotions surface when parents have a child with special needs, including guilt, anger, fear and anxiety. Many parents may feel guilty about experiencing such emotions and often have no outlet to express them. If social support is lacking, these conflicting emotions can lead to a variety of serious consequences including depression, marital problems, anxiety disorders and difficulties at work.

WHO AND WHERE

Among the most confusing aspects in seeking counseling is identifying an appropriate counselor and where to start to look for one. Counselors go by many names and the alphabet soup of initials, certifications, licensure and educational requirements vary from state to state. There are certain restriction concerning the use of the titles, but most consumers of counseling services are not familiar with them and as a result often enter counseling not fully aware of the credentials their counselor possesses. In an era where car buying has become a science and resources abound, the average consumer of counseling, on the other hand, has little knowledge of who and what is out there.

There are no legal restrictions on the use of the title "therapist" or "counselor." The term counselor is so overused that you can call a travel agency or insurance firm and be connected with a "travel counselor" to assist you. Individuals calling themselves counselor or therapist need not hold any specific educational training or degree. Be very wary if these titles are used without additional licensure, certification, or professional affiliations.

There are legal limitations on the use of the titles psychologist, licensed professional counselor/certified counselor, and licensed/clinical social worker. Psychologists are individuals who possess a PhD in psychology. Psychologists who provide counseling services generally have education and specialization in the field of clinical or counseling psychology. Counselors have a minimum of a masters degree in counseling. In some states, counselors may be licensed by the state board. Other states do not have licensure requirements in place and counselors may elect to become board certified through the National Board for Certified Counselors (NBCC). To become either licensed or certified, counselors must pass an exam and document their graduate training supervision and work experience. Consumers considering seeking counseling services from an individual who identifies himself as counselor should ask whether he is nationally certified (NCC) or licensed (LPC). If this person is neither, continue to look for a counselor who is certified or licensed. Social workers also provide counseling services and their licensure requirements also vary from state to state.

The titles can differ from licensed social worker to clinical social worker. Once again, be sure to check whether the social worker you are considering has the necessary accreditation that is required in your state.

Providers of counseling services often have numerous initials after their names that in some cases have meaning and other cases may be meaningless and misleading. Legitimate providers will share their certification or licensure background information willingly, including their identification numbers (usually needed for insurance reimbursement). A counseling professional's commitment to the certification and licensure process indicates that she abides by the code of ethics of that field. Commitment to the code of ethics protects the consumer of counseling services from unethical practices.

In addition to the issue of certification and licensure, counseling professionals should be affiliated with their parent professional associations. Along with the process of certification and licensure, this indicates a dedication to ethical and professional practice. In the field of psychology, the professional association is the American Psychological Association (APA). In counseling, the American Counseling Association (ACA) represents counseling professionals. Social Workers are represented by the National Association of Social Work (NASW).

Consumers considering counseling with an individual without certification, licensure and professional affiliation, should shop around some more. Many people have been hurt by so-called counselors because of their lack of knowledge about how to navigate through the sea of titles in the field.

WHAT

Some individuals are hesitant to seek out counseling for fear that "counseling won't work." Counseling is not a magic pill or tonic. When counseling doesn't work it is often due to a failure of the relationship between the client and the counselor.

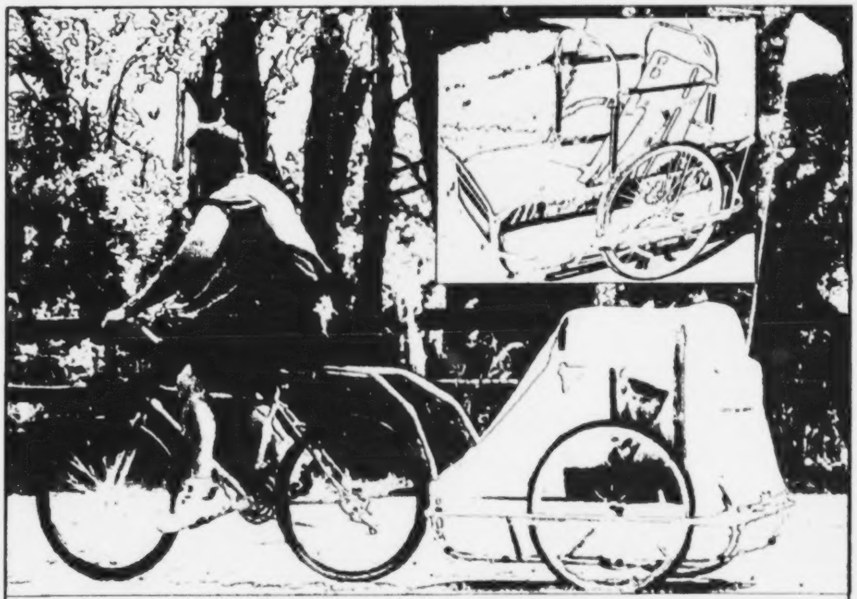
Often, counseling doesn't work because clients come into the counseling process with little or no idea of what to expect. Counseling is a process in which the client and the counselor collaborate to help the client work through difficulties. Effective counseling occurs when a therapeutic relationship is developed between the client and the counselor. A successful counseling experience involves the counselor imparting a feeling of empathy, respect, and attentiveness toward the client.

Many individuals come into counseling expecting a miracle cure to occur after only one session. This is unrealistic, as the counseling process is grounded in the counseling relationship and that takes time, just as any relationship does. In the initial session, the counselor may spend time obtaining history about the current problems that bring an individual into counseling. This is often frustrating for the client who seeks an immediate "answer" to his difficulties. A good counselor, however, assists clients by helping them find their own answers through exploration, clarification, and identification of options.

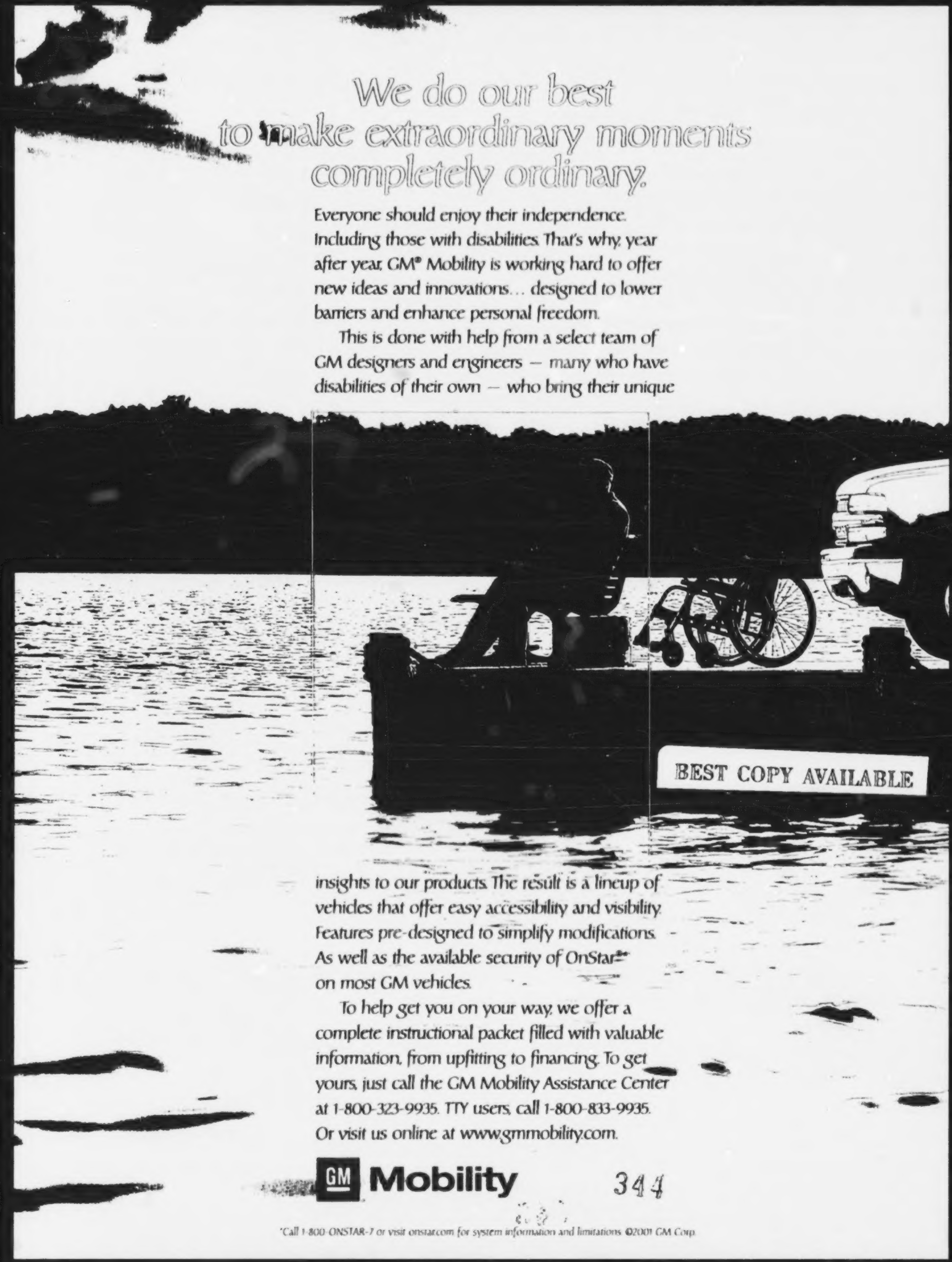
Many counselors will provide clients with an informed consent that outlines the parameters of what will occur during the counseling process. This will include information on the counselor's background, credentials, fees, length of sessions, and treatment methods. Counselors use different types of treatment methods, and clients should ask what to expect during the counseling process. If a counselor appears uneasy or hesitant in answering these questions, this is a sign that the search for the right match should continue.

An important aspect of counseling for individuals with children who have special needs is the degree to which the counselor has had experience in working with similar problems. This is an individual decision,

continued on page 45



Enjoy the out-of-doors together with a
CycleTote® Bicycle Trailer
Running Stroller
1-800-747-2407 www.cycletote.com
Satisfaction Guarantee/Lifetime Warranty



We do our best to make extraordinary moments completely ordinary.

Everyone should enjoy their independence. Including those with disabilities. That's why, year after year, GM® Mobility is working hard to offer new ideas and innovations… designed to lower barriers and enhance personal freedom.

This is done with help from a select team of GM designers and engineers — many who have disabilities of their own — who bring their unique insights to our products. The result is a lineup of vehicles that offer easy accessibility and visibility. Features pre-designed to simplify modifications. As well as the available security of OnStar®* on most GM vehicles.

To help get you on your way, we offer a complete instructional packet filled with valuable information, from upfitting to financing. To get yours, just call the GM Mobility Assistance Center at 1-800-323-9935. TTY users, call 1-800-833-9935. Or visit us online at www.gmmobility.com.

GM Mobility

*Call 1-800-ONSTAR-7 or visit onstar.com for system information and limitations. ©2001 GM Corp.

BEST COPY AVAILABLE

continued from page 43

but a good counselor who lacks knowledge about the child's condition, should be willing to research it. Giving the counselor articles and materials pertaining to the child's disease will help him understand the situation and the issues faced by the client. If the counselor does not seem open to this, the search should continue for another counselor. While the counselor may be more experienced in the counseling process, the parents are the experts on their child's condition.

MAKING THE CHOICE

The decision to seek counseling is often a tough one. Some people mistakenly see counseling as an admission of defeat or a sign of weakness. Entering into a counseling relationship means that an individual is willing to explore potential options and alternatives to her difficulties. The experience of being in counseling can result in a stronger support system and a sense of personal empowerment. **EP**

Audrey L. Canaff, PhD, NCC (National Certified Counselor) and LPC (Licensed Professional Counselor) is the UC Foundation Assistant Professor in the Counseling Programs Graduate Studies Division at the University of Tennessee at Chattanooga.

Resources

For more information on identifying a counselor:

American Psychological Association
750 First Street, NE, Washington, DC 20002-4242
(800) 374-2721 or (202) 336-5510
(202) 336-6123 (TDD)
http://www.apa.org/

American Counseling Association
5999 Stevenson Ave., Alexandria, VA 22304
(703) 823.9800
(703) 823.0252 (fax)
http://www.counseling.org/

Clinical Social Work Federation
P.O. Box 3740
Arlington, VA 22203
Confidential Helpline:(800) 270-9739
http://www.cswf.org

One of a kind

There are no formulas at Heartspring, just ongoing dedication to helping children with multiple disabilities achieve their fullest potential. Our multi-disciplinary approach recognizes each child as an individual and provides a plan customized for their specific needs. Your child is one of a kind. Why should their education be anything less?

Heartspring
School
Finding New Ways for Learning

8700 East 29th Street North · Wichita, Kansas 67226
www.heartspring.org

1-800-835-1043

Families in Pennsylvania, New York and New Jersey:

A Heartspring representative will be in your area **April 3-14** to discuss an educational setting unlike any other for your exceptional child. Call today to arrange your appointment.

Circle #35 or visit www.eparent.com/adinfo

research reflections

THE MYSTERY OF FAMILY RESEARCH:

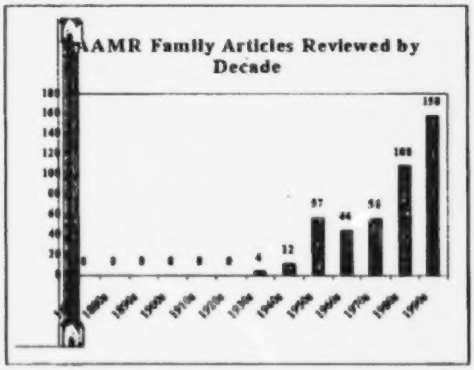
Parents magically change from invisible to prominent

by Jan Blacher, PhD

Consider this headline: "Parents and families of children with exceptionalities are now key players in the burgeoning field of family research." It wasn't always that way, especially for parents of children who were mentally retarded.

Parents of children with mental retardation and related disabilities enter the 21st century with more support than ever before. Most important, the legal mandate for a "free and appropriate public education" provides essential rights, albeit creating yet more responsibilities. New family supports are emerging to meet the child's vocational, social, and residential needs. Yes, of course there's still a way to go, but if we could go back 100 years, or even 50 years, we'd see how far we've come.

I did that time-traveling over the past century, although in the safety of a library and the national office of the American Association on Mental Retardation (AAMR). Over the last couple of years, colleagues and I reviewed more than 500 papers published by the AAMR. Dr. Bruce Baker and I selected 32 of the most meritorious for a just-released book, *The Best of AAMR: Families and Mental Retardation*. We uncovered a mystery of scholarly attention to families—its absence. For 60 years there were no AAMR journal papers that spoke to family issues and concerns. Indeed, from the first published paper in 1876 (in something lightly called *The Proceedings of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons)* until 1939 (in the curiously-named *Journal of Psycho-Asthenics*), the family was essentially invisible. The few early references to families were in articles pertaining to "family care," which ironically meant that the child or young adult with retardation would live in someone else's family! "Family care" in the 1930s was most similar to our current idea of foster care. Biological families were believed to have provided "poor parentage, physical disorder," or generally "bad environments" which contributed to, or even caused, their child's retardation. Those years, when retardation was disparaged and leading professionals advocated sterilization, institutionalization, and restrictive immigration, were not kind to natural families. It is not surprising that family members were essentially excluded from any participation in treatment.



Excluded from involvement in your child's treatment? This would be unheard of today, in practice, policy, or research (just peruse the issues of EP). Oddly enough, a paper that was published in 1939 by Harold Skeels and Harold Dye, *A Study of the Effects of Differential Stimulation on Mentally Retarded Children*, countered the anti-family sentiment and foreshadowed interest decades later in early intervention and parent training. Although this now-classic study did not involve biological families, the investigators did put forth a strong case for providing intense personal contacts in an enriched environment for very young children with retardation. The infants that Skeels and Dye moved from an orphanage to an institution, where they were mothered by staff and residents alike, had dramatic increases in IQ, from an average of 64 to 92!

By the 1950s and 60s, there was a surge of interest in families, although it would still be awhile before researchers recognized parents as worthwhile and accurate informants. Early papers were framed by clinical perspectives, focusing on parental reactions to a child with mental retardation, and advocating for addressing presumed parental distress through counseling. Some parent voices did begin to frame the research agenda, though. I especially like a 1959 paper by Mrs. Max Murray (as she identified herself), *Needs of Parents of Mentally Retarded Children*. A sophisticated needs assessment survey disseminated by researchers today could not come any closer to the mark than the observations Mrs. Murray shared. She wrote about six basic problems faced by families: difficulties

Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, and had been a researcher for over 25 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of retardation, dual diagnosis, and the transition to adulthood. Dr. Blacher has developed Research Reflections as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to Research Reflections and any suggestions you might have. Send email to: jan.blacher@ucr.edu.

in initially accepting the child's diagnosis of mental retardation; stress from the child's daily care needs; theological conflicts concerning acceptance of the child with disabilities; financial concerns; anxiety over lifetime care for the child; and inept, inaccurate and ill-timed professional advice. These issues still resonate today.

At this same time, beginning in the early 1950s, parents like Elizabeth Boggs were making their voices heard and actions felt through their fledgling Association for Retarded Children (ARC). By the 1970s this advocacy and service organization had more than a quarter of a million members and had become a major influence in the field.

By the 1980s family research skyrocketed, inspired by advocates, propelled by increased federal funding, and guided by new computer technologies. We found that the family paper cited most often was Keith Crnic, William Friedrich, and Mark Greenberg's 1983 *Adaptation of Families with Mentally Retarded Children: A Model of Stress, Coping, and Family Ecology.* This paper provided a conceptual framework for studying families that balanced the negative perspective embedded in the previous three decades of family research with a more positive one. Researchers were encouraged to pay more attention to the positive impact on families of a child with a disability, and advanced a stress and coping model in place of the previous focus on parental psychopathology. In addition, this paper reminded researchers that mothers had, for too long, been the sole focus of family research; some subsequent investigators met this challenge and undertook studies of fathers and siblings. The focus on coping has led other researchers to examine coping processes across cultures.

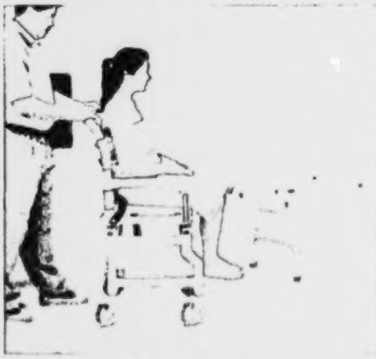
In a subsequent column I plan to elaborate upon the theme that "culture matters"; here let me just say that recent contributions to the family research literature have helped us to understand the differential impact of a child with disabilities on African-American, Chinese, and Latino families in the United States.

Another family issue that emerged in the 1980s was the parenting of adults with mental retardation. People with disabilities are fully participating in the phenomenon known as the "aging of America." As these people live into their 50s, 60s and beyond, their parents are faced with even longer parenting and an even more pressing need to plan for their adult child's future. Some of these parents face the challenge of parenting well after their own health begins to decline. Yet Marsha Seltzer and Marty Krauss pointed out, in

continued on page 48

Accessibility without renovation! Eliminate bathroom transfers!

from commode to
ower and never transfer!



Roll into position next to the tub and
inter-lock to the tub frame slide rails.

Entire seat slides over the tub.

Enjoy your shower!

hocked at the HIGH cost of a Ôroll-inÕ shower renovation... you need the ÒSLIDERÓ!

he SLIDER, bathing system eliminates costly Ôroll-inÕ shower renovations, bathroom transfers and other family members donÕt ose access to a bathtub. The SLIDER works with any standard built-in tub and rolls directly over any commode. Easy access ull out foot rest, adjustable tension back support, push handle, seat belt and open front, padded commode seat for easy access the perineal area are standard. The SLIDER utilizes 5Ó total lock casters and has two swing-away arm rests for lateral transfers. liding seat functions in either direction. Pediatric, Narrow and Extra-Wide models available. The SLIDER bathing system... **cost effective** alternative to bathroom renovation. SLIDER dimensions: Between arms- 17.5", Overall width- 21", Seat depth- 18", eat height - 24", Weight capacity: 250 lbs, Ships: UPS. Reclining ÒTilt-In-SpaceÓ model available. Master Card & VISA accepted.

Assistive Technology Inc. *530 S. Whittaker St. #240, New Buffalo, MI 49117*
Ph: 800 478-2363, 219 522-7201, Fax: 219 293-0202 E-Mail: info@pvcdme.com Web: www.pvcdme.com

Circle #21 or visit www.eparent.com/adinfo

research reflections

continued from page 47

their 1989 paper *Aging Parents with Adult Mentally Retarded Children: Family Risk Factors and Social Support*, that mothers' well-being was high—as high, in fact, as in mothers considered in the broader gerontology literature who were caring for their own aging parents. One possible explanation for such satisfactory well-being is that co-residence of adults with retardation with their parents has a salubrious effect. Indeed, Tamar Heller, Alison Miller, and Alan Factor noted in a 1997 paper, *Adults With Mental Retardation as Supports to Their Parents: Effects on Parental Caregiving Appraisal*, that "[p]arents who received support from their son or daughter with mental retardation experienced greater caregiving satisfaction and less caregiving burden." Perhaps more than ever before, parents of exceptional people can enjoy their caregiving responsibilities and appreciate their offspring's positive impact.

At the same time that the research spotlight cast a flattering light on parents of children with mental retardation, new players entered the stage—parents who themselves had mental retardation. Although there has been intense attention paid in the past two decades to parents with retardation, this population was actually of interest to researchers as long ago as the 1920s. A particularly forward-looking 1947 paper by Phyllis Mikelson, *The Feebleminded Parent: A Study of 90 Family Cases* examined characteristics of families with at least one child and one parent with mental retardation. This study yielded a bold and prescient finding—that parents with both mental retardation and serious mental health problems were much less likely to provide adequate child care. This foreshadowed today's intense professional and practitioner interest in dual diagnosis of mental retardation and mental disorders, another topic I plan to address in a later column.

Looking back over the 125-year history of the American Association on Mental Retardation and the family research that germinated and finally blossomed during that time, one can see that parents were not pulled, magically, from a seemingly empty hat. Rather, the visibility that parents now have, influencing the focus of research, services, and policy, was hard-earned—it built upon the faith and effort of forward-looking scholars, professionals, and parents. Looking ahead, you, as exceptional parents, are writing the next chapter. EP

Never in my Wildest dreams...

"WHEN I FIRST CAME TO CROTCHED MOUNTAIN OVER 10 YEARS AGO, activities that were second nature prior to the automobile accident were challenging tasks. Today I am a college graduate and also have my drivers license.

Never in my wildest dreams would I have been able to do half of what I've achieved without the encouragement and help that I received at Crotched Mountain! I want to thank everyone at Crotched Mountain for helping me get my life back!"

—*Brent Reagan '93*
Crotched Mountain School

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@cmf.org

CROTCHED MOUNTAIN
OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #34 or visit www.eparent.com/adinfo

be a hero for the tiniest babies

Alex Kingston
of NBC's "ER"

Photograph Courtesy of Amy Etra

"I know how important it is for babies to get a healthy start, like my daughter did. But today, sadly, 1,232 babies won't be so lucky — because they're born premature. Some are so small they fit in the palm of a hand. Many of these babies will have to struggle just to survive. But the March of Dimes is there helping them win their fight. You can help, too."

March of Dimes
WalkAmerica
Saving babies, together

Join March of Dimes WalkAmerica.
Call 1-800-525-WALK or visit
www.marchofdimes.com/walkamerica
and register today!

Circle #56 or visit www.eparent.com/adinfo

Universal Newborn Screening

In 1961, Dr. Robert Guthrie of the University of Buffalo developed a laboratory test to detect phenylketonuria (PKU) in newborns. PKU is an inherited metabolic disorder resulting from an enzyme deficiency; if left untreated, it results in profound mental retardation. In 1963 Massachusetts became the first state to mandate screening for PKU, which can be treated by lifelong dietary management and counseling. The National Association for Retarded Children (now The ARC), the Children's Bureau and the Kennedy Foundation were foremost among the organizations that pushed for widespread adoption of the Guthrie test, and by 1966 it was required for all children by all 50 states and the District of Columbia.

Dr. Guthrie and other researchers continued to develop newborn screening (NBS) tests to detect many more disorders, and each state decided what screens would be available for its newborns. Significant disparities resulted; in 1997, in Massachusetts, infants were tested for 10 or more disorders, while Utah's babies were screened for three. Montana and South Dakota each mandated three tests and offered one other by special request only. In the same period, with the introduction of ever-smaller and more powerful microprocessors, technology and equipment became significantly more sophisticated. This permitted testing that had not been feasible before. A process called tandem mass spectrometry (tandem MS, MS/MS) can now run tests for nearly 40 disorders at one time. None are curable, but all are treatable.

In the last two years, many states have expanded their NBS programs. Almost all Pennsylvania hospitals now offer the full spectrum of testing, although the law mandates testing for only six. Massachusetts routinely screens for more than 15 disorders and is running a pilot program offering 30+ tests. Wisconsin has almost tripled availability, from 7 tests to 20. Yet universal NBS still engenders much controversy, and there are many issues to be resolved before consensus can be reached on how the US will move forward.

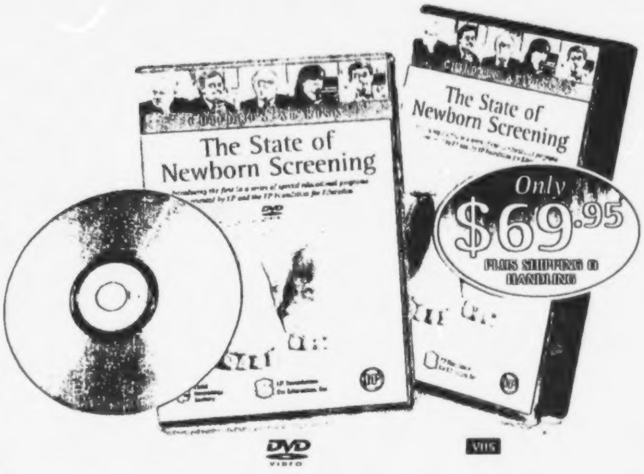
The data tells us that of the four million babies born in the US each year, ten to twelve thousand may have one or more of these detectable...and treatable...disorders

ISSUES: These may be economic, political, professional, sociocultural, religious. Capital spending, training, payment policies, long-term follow-up; insufficient hard financial data; union issues; professional knowledge levels and practice habits; citizen knowledge, and cultural and religious beliefs and practices; insurance, managed care companies, Medicaid, ChIP programs, the uninsured–all these and many more must be part of discussions and resolution.

With the current system, a child born in Louisiana with galactosemia will likely live a life marked by mental retardation and other special health care needs, while similarly affected children born the same day in most of the rest of the country will receive immediate treatment and become productive members of society. The data tell us that of the four million babies born in the US each year, ten to twelve thousand will have one or more of these detectable disorders, an almost-negligible number. The overall cost or benefit to our society, though, will vary wildly from one child to another because of the patchwork of screening availability. We as a nation must find a way to embrace universal NBS and make it routine for all children born in the US. More than that, it is downright wrong not to do so when it has proven its worth time and again!

It is a question of education and awareness. Research shows that the average couple planning to have children does not know anything about existing screening programs, much less the capabilities offered by tandem MS, largely because OB/GYNs, pediatricians, genetic counselors and related professionals are not familiar with universal NBS. The education gap relates to professionals and consumers, rich and poor, people of every race, religion and ethnicity. Few people know much about any of the issues. Worse, among the people who do profess knowledge of NBS and the issues, a good deal of what they "know" is wrong.

The information you need on Newborn Screening is finally available on DVD and video


The State of Newborn Screening
The State of Newborn Screening
Only
$69.95
PLUS SHIPPING & HANDLING
DVD
VHS

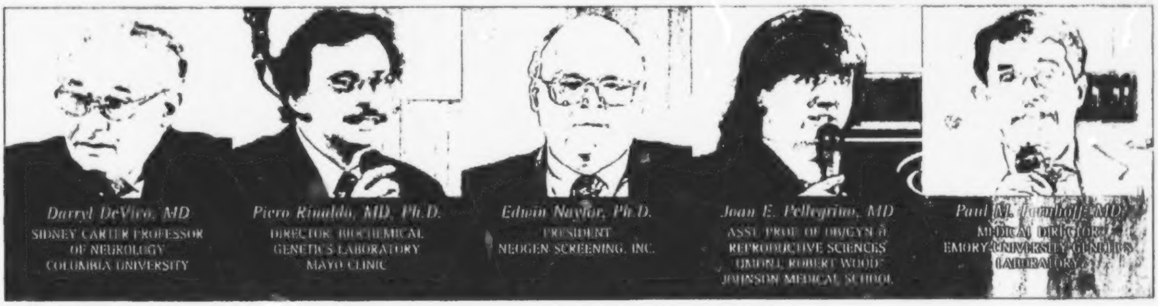
Children at Risk:
The State of Newborn Screening

is now available on DVD and VHS. Introducing the first in a series of special educational programs presented by EP and the EP Foundation for Education, Inc., a 501(C)3 Not For Profit Corporation.

EP Foundation for Education, Inc.
Child Neurology Society

Newborn screening can detect up to 39 metabolic disorders from one blood spot. All are treatable when diagnosed at birth, offering the chance for a full and productive life.

Leading medical and scientific professionals are gathered to provide the most current information available. You can view this valuable resource at your convenience and the DVD is indexed so that key topics are easily accessible.



Darryl DeVivo, MD
SIDNEY CARTER PROFESSOR OF NEUROLOGY
COLUMBIA UNIVERSITY

Piero Rinaldo, MD, Ph.D.
DIRECTOR, BIOCHEMICAL GENETICS LABORATORY
MAYO CLINIC

Edwin Naylor, Ph.D.
PRESIDENT
NEOGEN SCREENING, INC.

Joan E. Pellegrino, MD
ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES
UMDNJ, ROBERT WOOD JOHNSON MEDICAL SCHOOL

Paul M. Fernhoff, MD
MEDICAL DIRECTOR
EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA | MasterCard | CHECK

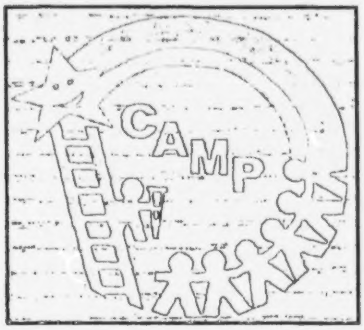
To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #50 or visit www.eparent.com/adinfo

SUMMERTIME SUMMERTIME SUM SUM SUMMERTIME!

Camp C.A.M.P. A Unique Learning Experience

**by Larry McClaugherty, RPh, MPH, FASCP; Lynn Vu, PharmD;
Tracy Virtue, PharmD Candidate;
Sherry Womack, PharmD Candidate**



The Children's Association for Maximum Potential (C.A.M.P.) was founded in 1979 by Dr. Chris Johnson, then a pediatric resident at the United States Air Force Medical Center in San Antonio, TX. Doctor Johnson was inspired to start C.A.M.P. when, one spring, a young boy named Matt came to her for a summer camp physical and returned to her that fall with the sad news that he had been "too handicapped" to attend the camp. It was for children with disabilities, but only for those who were completely self-sufficient. Matt did not fit the criteria because he could not tie his own shoes or fasten his leg braces. It was then that Dr. Johnson decided it was time to push forward a long-time dream of having a camp that accepted all children, regardless of their disability. Now in its 23rd year, Camp C.A.M.P. hosts children from all over the United States. C.A.M.P. is a non-profit organization that puts 92 cents of every dollar donated back into the organization; only 8 percent goes to administrative costs. To make this possible, many people come together and volunteer their time. During any given week at C.A.M.P. there are more than 150 staff members, including counselors and medical volunteers.

A Typical Day at C.A.M.P.

A typical day at C.A.M.P. is long and fun. Everyone starts the day early. Counselors get up, get ready, and then get their campers ready for Flagpole. At Flagpole each tribe (group of campers) gets together and shows its spirit by singing camp songs and cheers. Flagpole starts at 8:00 a.m. and is followed by breakfast at 8:15 a.m. At each meal, medical staff members sit with their assigned tribe and administer medications. Campers have two morning activities, such as horseback riding, swimming, canoeing, archery, and arts and crafts, before lunch. Throughout the day medical staff people participate in activities with their tribes, so that medical help is always available in case of an emergency. After lunch, campers and counselors have a rest period before afternoon activities. Special activities are planned for after dinner, ranging from karaoke to wacky Olympics to dance. Then everyone hits the cabins for showers and bedtime. Once the campers are back in the cabins the medical staff comes for night rounds. At night rounds each camper gets bedtime medication and a brief check-up to address any medical issues that might have arisen during the day. The medical staff talks with counselors about their campers to gain more information and offer suggestions. Around 9:30 p.m. the entire medical staff meets at the infirmary for a night round meeting led by Dr. Chris. Concerns for individual campers are addressed, suggestions and plans of action are made for some, unique accomplishments of campers are discussed, and the events of the day are reviewed. Assignments are made for the medical staff that will be on call that night and the following day.

Specific Disabilities seen at C.A.M.P.

C.A.M.P. is not a typical summer camp. Even though the children participate in the usual camp activities, the standard camper has multiple disabilities. Among the more common at C.A.M.P. are cerebral palsy, muscular dystrophy, spina bifida, autism, mental retardation, Down syndrome, ADD/ADHD and seizure disorders. Campers might also have such rare disorders as fragile X, Wolf-Hirshorn syndrome, tuberous sclerosis or Angelman's syndrome.

For the healthcare provider, C.A.M.P. allows a practical first-hand learning experience with various developmental disabilities. In addition, a developmental disabilities review course is available to all healthcare volunteers and counts as continuing education credits for many of the professionals. The course is offered during the volunteer week at camp and includes five hours each day of didactic classes about each major disability.

Roles and Responsibilities

One of the most impressive aspects of this camp is the amazing leadership and maturity demonstrated by the young people who

C.A.M.P. campers get some advice from their counselor.

serve as counselors and support staff. These young people, many only 15 or 16 years old, are volunteering their time to take care of others. Each counselor is responsible for one camper. They never leave campers' sides during the day and sleep in the beds next to them at night. Counselors get campers ready, make sure they eat and drink, bathe them, play with them, help with toileting, and handle many other tasks. Counselors often find it hard to part with their campers at the end of the week after spending day and night bonding with their new friends! Destiny Waiter, a counselor this summer, has adopted a quote she once heard on the radio as her own personal creed: "Service is the price you pay for the space you occupy." Says Destiny about being at camp, " you can really affect someone's life. When a child with autism tries to bring you into his world, it's the coolest thing!"

A full medical staff is on hand at all times. Doctors, nurses, medical students, pharmacy students, nursing students, speech therapists, physical therapists, and occupational therapists are all present. These disciplines come together to help make C.A.M.P. a safe and enjoyable environment for everyone. Specifically, the role of physicians is to examine all the campers and periodically check their health status. Physicians also help the other members of the medical staff, including the nurses, whose duty is to document and administer medications and treatments as necessary. Pharmacy students may also help in this role and are available to answer questions about medications and their administration. Therapists and social workers are very involved in setting and

continued on page 54

353

VISION By VIEWPOINT MOBILITY

The **VISION** Advantage:
- Rear entry design doesn't limit you--park and go anywhere
- Not a bulky full-size van-- VISION can fit in a small garage
- Everybody can ride-- seats up to 7 passengers or 2 wheelchairs
- Conversions available on Chrysler and Ford minivans

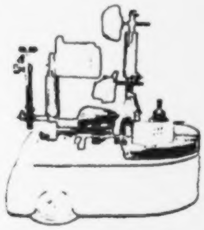
Let VISION take you on the road to opportunities.

For a **Free Video** or a
personal demonstration of the **VISION** call
Toll Free 1-877-368-6022

Circle #80 or visit www.eparent.com/adinfo

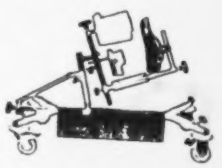
Early Childhood Mobility
Mini Go-Bot's

Century Stander


Stanford Standard

***Note*: Standing frames work with either Go-Bot**

Yellow Go-Bot


GB-I Gait Trainer
(can be customized)

Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com

Circle #51 or visit www.eparent.com/adinfo

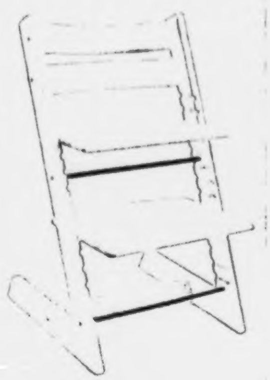
THE Adjustable® Bath Chair
by DURALIFE

30L-B
30M-B
TWO great styles to choose from!
Model 20
Model 350
Pediatric Shower/ Commode Chair

- 9" leg extensions available.
- Adjusts to multiple positions for individualized comfort.
- Safe, quick push-button adjustment mechanism located out of child's reach.
- Highly-durable, comfortable mesh fabric is easy to clean and dries fast.
- Safety straps included for those who require extra support.

DURALIFE, INC.
Call Toll Free: 1-800-443-5433
Fax: 570-323-9762
E-mail: duralfe@aol.com
Website: www.duralife-usa.com

Circle #38 or visit www.eparent.com/adinfo



We Like Making Kids Happy ...

Send For Free Catalog

equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094

E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #40 or visit www.eparent.com/adinfo

Resources for Choosing Camps

AMERICAN CAMPING ASSOCIATION
(800) 428-CAMP
http://www.acacamps.org.
ACA monitors camps in all 50 states to see if they meet 300 standards for health, safety and program quality. Over 2,000 camps, including those with special needs programs, have earned ACA accreditation. The ACA Web site offers informative articles on choosing a camp as well as a database that lets parents do a search for camps using a variety of criteria.

THE EPILEPSY FOUNDATION
(800) 332-4050
http://www.efa.org
Some Epilepsy Foundation affiliates offer summer camping and family retreat programs, whether they run the camps themselves or make arrangements with local camps for a special camping session for children with seizures. In many cases, scholarship money is available through the local affiliate and also through the Epilepsy Foundation's national office for children with seizures to

continued from page 53

keeping track of goals for campers and helping them to build important skills needed for independence. At the end of the week all campers who have met their goal receive a ribbon recognizing their progress. Goals for some campers were broad, such as socializing with other children; or experiencing an activity they have never tried before. Others had more specific goals such as learning how to shake hands, for example, or tie shoelaces. The McConleys brought their daughter, Kaly, to camp this summer hoping that she would meet their goal for her of learn the meaning of the word "vacation." To aid Kaly in the process, a physical therapist at camp made miniature flash cards using pictures associated the camp activities. The therapist used the pictures to represent vacation in such a way that Kaly could make the connection that she was on vacation. At the end of the week, Kaly met her goal when she proudly announced, " VACATION IS FUN!" Commenting on how proud and happy the parents are when they find out their child has met a new goal, occupational therapist Shana Scheib said, "You get to see what camp does for the parents."

Interdisciplinary Approach

The lines between nurse, doctor, and pharmacist are not clear at C.A.M.P. Professionals play a definite part but also step outside their traditional roles. Every discipline brings something unique to the team and that knowledge is shared to benefit everyone. Each person on the medical term leaves C.A.M.P.

continued on page 56

attend the camp of their choice. Contact the Epilepsy Foundation for your local affiliate. The Foundation's Web site also has articles on camping and sells brochures both for parents and for camp counselors on camping for children with seizure disorders.

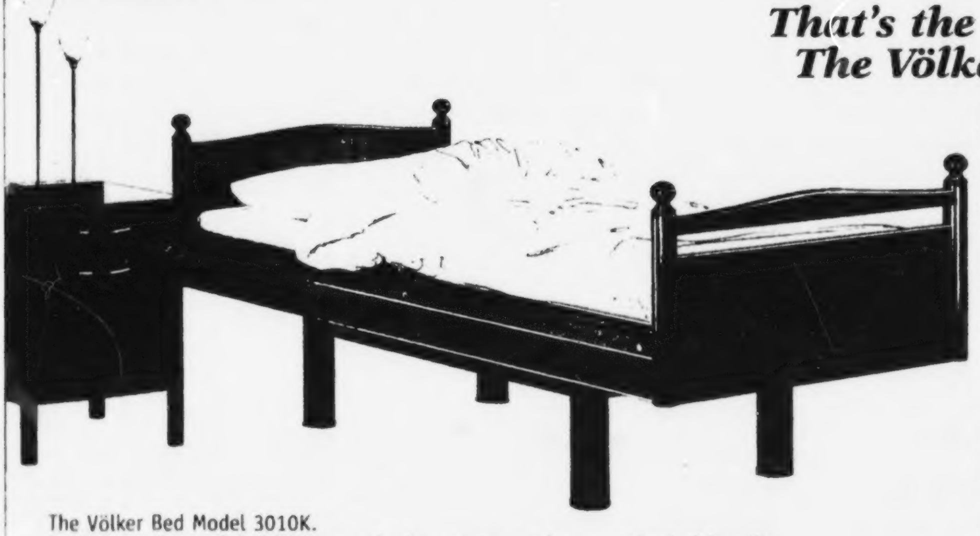
UNITED CEREBRAL PALSY
(800) 872-5827
http://www.ucpa.org/
Some UCP affiliates offer camping experiences. Contact your local UCP affiliate for more information.

MUSCULAR DYSTROPHY ASSOCIATION.
(800) 572-1717
http://www.mdausa.org
Each year, MDA supports nearly 90 summer camps across the country for youngsters with neuromuscular diseases. MDA camps offer a wide range of activities specially designed for young people who have limited mobility or use wheelchairs as well as the swimming, baseball and horseback riding and arts and crafts.

NATIONAL EASTER SEALS SOCIETY
(800) 221-6827
http://www.easter-seals.org
Easter Seals offers 140 accessible camping and recreational facilities nationwide, serving all ages and abilities. There are three types of camping programs including day, residential and respite camps. Day and residential camps provide arts and crafts, sports and games. Respite camps serve children and adults with the most involved physical, emotional, cognitive and behavioral disabilities. The Easter Seals Web site also features articles on choosing a camp or summer program.

DIABETES CAMPING ASSOCIATION (DCA)
http://www.diabetescamps.org/
and
DIABETES123/
CHILDREN WITH DIABETES
http://www.childrenwithdiabetes.com/camps
Listings of camps in the US and Canada for children coping with diabetes providing active and safe camping environment and stressing diabetes education management skills.

VÖLKER **The health-care bed in disguise.**



That's the beauty of The Völker Style ...

Beautiful homelike appearance of fine furniture — with the features you've asked for:
- **Concealed siderails**
- **4 hidden swivel casters**
- Height adjustable
- Head and leg adjustment
- Secure electric braking system

The Völker Bed Model 3010K.
Full function with hidden swivel casters and concealed siderails.

For more information call 1-800-321-4240
Also ask about our low-height options.
Visit our Web site at **www.hertzsupply.com**

Hertz SUPPLY

Circle #48 or visit www.eparent.com/adinfo

355

The BEST strollers in the WORLD!
by Baby Jogger
Our Special Needs strollers are lightweight, easy to fold, and a joy to push...
BABY JOGGER
www.babyjogger.com • (509) 457-0925
Circle #74 or visit www.eparent.com/adinfo

Anchors in different locations when needed.
SUREHANDS
Gary L., accountant, Warwick, NY - Becker's MD

At last, a Lift & Care℠ system as versatile as a pair of hands...and portable, too.

It's a motorized transfer device,
a positioning tool *for posture seating*,
a bathing support,
a hygiene helper *for toileting or diapering*,
a floor space-saver,
a standing support *for some*,
a dressing assistant,
and a back-saver *for carers*.

SUREHANDS LIFT & CARE SYSTEMS
Portable and permanent solutions for homes and workplaces.
1-800-724-5305
e-mail: info@surehands.com • website: www.surehands.com

Circle #73 or visit www.eparent.com/adinfo

continued from page 55

with a better understanding of fellow health care professionals and a true understanding of " interdisciplinary teamwork."

Something for everyone

For the parents, C.A.M.P. allows much-needed respite. Janet Troy from Houston said, "I was happy that our daughter, Autumn, got individual attention from a counselor around her age. It's nice that she gets to spend time with other children with similar problems while her father and I got to enjoy a little time alone."

Campers have one counselor each who is always by their side.

Part of the reason C.A.M.P. is such a big success is that everyone working there is so dedicated. "This is my fifteenth summer at C.A.M.P. I consider C.A.M.P. my family," said Cat Hadovsky, the assistant camp director. "I like to see the campers learn and have fun they normally wouldn't have and get one-on-one attention they might not get anywhere else. I also like to see the teenage counselors blossom as young people. People may say negative things about teenagers today but give them a purpose like C.A.M.P. and you can really see them shine."

Many of the volunteers do not view C.A.M.P. as work but instead feel it is a privilege, and they also feel a sense of pride for giving so unselfishly of themselves. Ben Johnson, a counselor for the past four years said, "You know that you can help so many people and get so much out of it yourself. I think all the counselors would agree with me when I say that the reason I come back is to see the smiles on the campers' faces and knowing that we're helping to make them happy." EP

Larry McClaugherty, RPh, MPH, FASCP, is the parent of a son with special needs who attended Camp C.A.M.P. and a Preceptor for the University of Houston College of Pharmacy, TX. Lynn Vu, PharmD, Tracy Virtue, PharmD Candidate, Sherry Womack, PharmD Candidate, of the University of Houston College of Pharmacy, TX, particpated in C.A.M.P. as part of the interdisciplinary medical team.

abilities EXPO

Florida
Broward County
Convention Center
March 22-24

New York Metro
New Jersey
Convention Center
April 12-14

Southern California
Long Beach
Convention Center
June 7-9

Greater Cleveland
I-X Center
July 19-21

Chicago Metro
Donald E. Stephens
Convention Center
August 16-18

New England
Bayside Expo Center
September 20-22

Northern California
San Mateo County
Expo Center
November 22-24

Education and *Equipment* to *Empower.*

Come **sample products** and **talk one-on-one** with service providers. As our guest you can attend **complimentary educational workshops** on everything from better sex to better jobs. Or perhaps you would like to see the power of new technologies in our **Access Ability Pavilion.** There are many options for you at **Abilities Expo.**

For more information please call (800) 385-3085 or (218) 723-9130 outside of the USA.
www.abilitiesexpo.com

BEST COPY AVAILABLE

abilities EXPO

PRESENT THIS COUPON
FOR FREE ADMISSION

[ADMIT ONE]

Bring coupon to any **2002 Abilities Expo** and save the $5 on-site registration fee.
Coupon must be filled out to be valid and may be photocopied for additional registrants.

NAME: ____________________

ADDRESS: ____________________

CITY: ____________ STATE: ______ ZIP: ____________

For information call:
(800) 385-3085
(218) 723-9130 (outside USA)

Produced and Managed by:
ADVANSTAR
COMMUNICATIONS

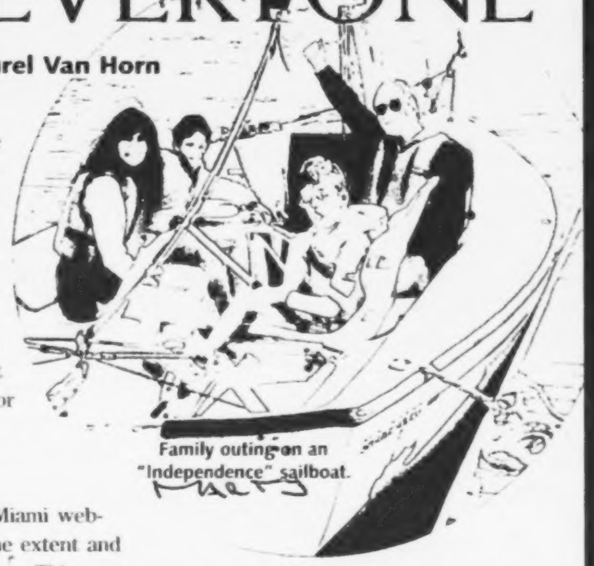
All events are wheelchair accessible.

© 2002 Advanstar Communications Inc. All rights reserved.

Circle #17 or visit www.eparent.com/adinfo

SHAKE-A-LEG MIAMI
SAILING FOR EVERYONE

Article and photos by Laurel Van Horn



Family outing on an "Independence" sailboat.

I had read about the Access Dinghies from Australia that made sailing possible for virtually anyone and even met Graeme Raynor, their "Johnny Appleseed," but seeing them in action last January was a real thrill. Shake-A-Leg Miami now has 14 of these colorful, little boats, which can even be sailed with a joystick. Every Sunday afternoon kids of all ages, sizes and abilities converge on the facility in Coconut Grove for basic instruction and a recreational sail. What makes this program so great is that the kids are able to take to the water on their own, guiding the dinghies themselves within the protected waters of the marina. The smaller children, including a set of twins, were sailing in pairs; the older ones, single-handed. Afterward, they all pitched in to wash the dinghies and put away equipment, an integral part of the sailing experience. For some, this could be the start of a lifelong love of sailing. Shake-A-Leg has a variety of programs these youngsters can graduate to, including competitive sailing in local regattas. And there's a whole fleet of larger boats for them to grow into at this universally accessible watersports facility. At present there are eight 20-foot "Independence" sailboats designed for wheelchair users, as well as three 23-foot "Sonar" sailboats, the type most commonly used worldwide for disabled sailing competitions.

SHAKE-A-LEG'S HISTORY

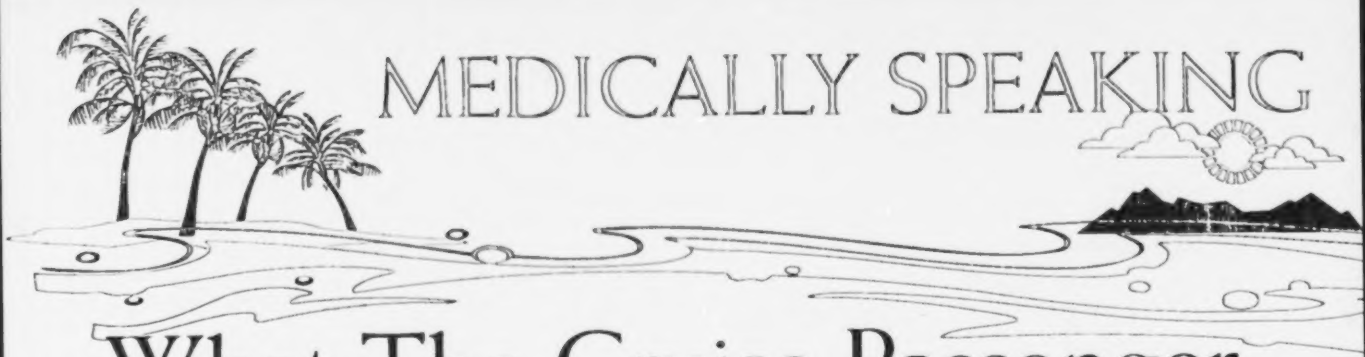
If you visit the Shake-A-Leg Miami website, you will be amazed at the extent and inclusiveness of their programs. This was not achieved overnight, of course. Harry Horgan, founder and executive director, began the original Shake-A-Leg in Newport, Rhode Island in 1982 following an accident which left him paralyzed. A lifelong sailor, he teamed up with a naval architect and yacht manufacturer to design a boat that would be universally accessible. Now known as "Independence" sailboats, these watercraft cannot sink or capsize and have two special seats, with all lines running into the cockpit. With a capacity of six, they're also very family friendly.

In 1990 Shake-A-Leg expanded its operation to Miami, where initially it catered only to adults with physical disabilities. The center then decided to reach out to children with disabilities, before opening its doors also to "at risk" youth. Along the way public-private partnerships developed, so that Shake-A-Leg Miami now operates in conjunction with the

continued on page 99

425
421
424
427

Access Dinghies in the Miami waters.



What The Cruise Passenger SHOULD KNOW

By Linda Allen, MA, MCC

Cruise passengers may or may not come on board prepared for their cruise. Some embark with little or no forethought to the situations they may encounter. Even passengers with complicated medical conditions may book a cruise with the thought, "There is a doctor and hospital onboard so they can take care of me if I need attention while at sea." These same people may board the ship with medications removed from their original containers and with little or no written medical history. Piecing together a complicated jig saw of medical needs with limited resources can strain the medical facilities of any vessel and cause great anxiety for the patient.

In an attempt to provide cruisers with the medical information they need before boarding, we offer the following suggestions.

KNOW BEFORE YOU GO

Too often, the lure of a beautiful brochure showing exotic destinations is all that a cruise passenger sees, while the section at the end is disregarded. This section, which outlines the terms of the contract between the cruise line and the cruise passenger, is written in simple and straightforward language. Even the more detailed cruise contract that is delivered with every set of cruise tickets can be easily understood by most passengers. The problem lies in getting them to understand that they are in fact entering into a contract with the cruise line. With the exchange of money, the passenger as well as the cruise line assumes distinct obligations.

Most cruise contracts specify that the cruise line must be notified of any medical condition that can impact the health and safety of the passenger or make them unfit to travel. This includes pregnancy, which some passengers see as a non-medical condition. In fact fitness to travel is such an important area within the cruise contract that it is one reason a passenger can be denied boarding at the embarkation port. It can also necessitate emergency disembarkation en route.

DO YOUR RESEARCH

Do a bit of research about the destination to determine if any special medical precautions are needed. Even better, consult your physician or a travel medicine specialist 6 to 8 weeks before your trip. A physician familiar with travel medicine will address concerns that include not only your current state of health but also any needed immunizations, health precautions, or medications that should be added to your first aid kit.

Plan for the weather and terrain. Make sure that you pack appropriate clothing for any expected circumstance and sensible shoes for your destination.

Keep abreast of the political climate and any unrest in the area you will be visiting. Pay attention to any advisories that are placed in the ship's newsletter about the ports of call.

HOW TO CHOOSE THE RIGHT SHIP

The passenger with physical disabilities or medical concerns should carefully select a travel consultant to assist them with their cruise plans. The tried and true methods of asking friends, family and members of support groups are still the best ways to find a qualified agent. It is less important to find

continued on page 60

SATH-Breaking Down Barriers To Travel

Since 1976, the non-profit Society for Accessible Travel & Hospitality (SATH) has been raising awareness of the needs of all travelers with disabilities, and removing physical and attitudinal barriers to travel both in the US and abroad. Members include consumers with disabilities, travel professionals, and other individuals and corporations who support SATH's mission. For more information, contact SATH at 347 Fifth Ave., Ste. 610, New York, NY 10016; phone: (212) 447-7284; fax: (212) 725-8253; e-mail: sathtravel@aol.com. SATH's Web site http://www.sath.org contains a wealth of travel-related information, some of which includes fact sheets on travel with different disabilities; selected feature articles from *OPEN WORLD magazine*, SATH's quarterly magazine; and travel and access information with lists of publications, government resources, disability travel Web sites; accessible transportation rental agencies and a directory of travel and tour operators specializing in travel for people dealing with specific disabilities. EP wishes to thank SATH and Laurel Van Horn, executive director of SATH and editor of *OPEN WORLD*, for contributing these two articles.

continued from page 59

someone who is a specialist in dealing with disabilities than to find someone who is excellent at their profession. Their skills and experience with their suppliers will allow them to meet your needs effectively. First and foremost, make sure that your agent is someone you enjoy talking to, feel comfortable with and trust. Experienced, qualified agents will often have the credentials of MCC or CTC after their name. The MCC designation signifies that the agent has met the requirements of CLIA (Cruise Line International Association) to be designated a Master Cruise Counselor. The trade industry has a broader training program for full service agents or cruise only agents which earns them the title of Certified Travel Counselor. Either of these designations indicate that the agent has invested a great deal of time, effort and money in making sure that they can serve clients effectively.

With the help of your agent you can then begin the process of selecting the correct ship for you. It is wise to plan as far in advance as possible to ensure that you are able to get the ship and itinerary that is of greatest interest to you. If you require a special wheelchair accessible cabin you should plan on reserving about a year in advance. This is especially true if you want a suite or an inexpensive inside cabin, as these are the first to sell on modern ships. There are very few wheelchair accessible suites in the market so make sure you discuss the type of cabin that you want early in your discussions with your agent.

> Refunds when given for unforeseen covered expenses are paid by insurance companies and not by the cruise line.

A good rule of thumb to discuss with your agent is that the newer cruise ships are generally the most disability friendly. The cruise lines voluntarily strive for compliance with the guidelines of the Americans with Disabilities Act and many of them offer some of the most barrier-free accommodations in the travel industry. The new ships also are larger and able to afford more space for the medical facility. It is also a good idea to ask if the ship is marketed primarily to the North American market. These ships will have English speaking medical personnel and will meet the expectations of the North American passenger. Don't forget to confirm that the cruise line is a member of ICCL-International Council of Cruise Lines.

Once you have narrowed down the field of possible ships, dates and itineraries, it is time to start looking at the ports of call. It is not a good idea to choose an itinerary with tender calls if you have mobility concerns. Tenders are much smaller boats that are used to shuttle passengers from the cruise ship to the shore. Most require the use of stairs or at the very least a transfer from the relatively stable cruise ship to a bobbing tender. Try to pick an itinerary where the ship docks at all or most of the ports.

Purchase Travel Insurance

Many passengers feel that if they have an unusual or tragic event in their lives that prevents them from travel that the cruise line should offer them a full refund. Refunds when given for unforeseen covered expenses are paid by insurance companies and not by the cruise line. Therefore, passengers who must cancel a cruise due to circumstances such as illness or death of a family member will not be reimbursed without travel insurance. The penalties accessed by each cruise line are clearly spelled out in every full cruise brochure. If a passenger purchases a cruise without a full cruise line brochure, they should ask for one before final payment is due so that they can read the terms and stipulations for themselves before they are in the penalty point range.

The purchase of travel insurance does so much more than protect the purchase price of a cruise. In addition comprehensive travel insurance policies offer such peace of mind

With the Creepster Crawler, You Can Watch Your Child Crawl for the First Time!

Children lacking head control, the ability to roll over or belly crawl have gained mobility with the ***Creepster Crawler.*** Using this light, innovative device, hundreds of children around the world are crawling, working more productively with their therapists, and gaining a head start to more advanced mobility in the future.

The ***Creepster Crawler*** is an ideal solution for youngsters with debilitating conditions such as ☐ Spina Bifida ☐ Down Syndrome ☐ Cerebral Palsy ☐ TBI, and ☐ developmental delays. Children with tracheostomies and G-Tubes also are successful users of the ***Creepster Crawler***.

The ***Creepster Crawler***'s frame has a padded platform that can support a parent or therapist from above, making it easier to work with the child on weight-bearing, weight-shifting, reaching and creeping. Front shoulder, chest and rear straps can be adjusted for individual fit.

Please visit our Worldwide Web site at www.red-enter.com for additional details and a video demonstration of the ***Creepster Crawler***.

Call for a Brochure!
1-800-577-1317
Fax:**1-602-242-9211**
or email us at info@red-enter.com

RedBarn
ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.red-enter.com**

CAUTION: Children should not be left unattended in the Creepster Crawler.

Circle #66 or visit www.eparent.com/adinfo

items as medical evacuation, travel accident or illness coverage, return of mortal remains and travel assistance. Travel insurance can be purchased directly through the cruise line or through a travel agent. Any policy that is purchased should cover pre-existing conditions as well as default of suppliers or carriers. Even when a major cruise line with great financial stability is involved, air carriers or others who are responsible for part of your vacation may be affected by such things as strikes and natural disasters, making them unable to provide the contracted service.

NOTIFY OF SPECIAL REQUESTS

Most cruise lines have the ability to accommodate a large number of special requests: such things as cribs in a stateroom, special diets and wheelchair accessible cabins. Some lines have special equipment available for hearing and sight-impaired guests, but guests need to request this ahead of time due to limited supply. All of these things should be reported by the passenger to the travel agent, who can then direct the special request to the correct department within the cruise line. This should be done at the time of the original booking.

Even clients who do not require an adapted cabin but who use a wheelchair, walker or cane full or part-time should report this to the agent so that the cruise line can be notified. This assists in priority embarkation and disembarkation as well as convenient placement in the dining rooms. Physically challenged passengers should be placed as close to an elevator as possible and every effort should be made to place them near their dining room.

If there are any medical, physical or dietary conditions including but not limited to the following, report them at time of booking: Mobility Impairment, Vision or Hearing Impairment, Pregnancy, Allergies, Diabetes, Dialysis, Oxygen Use, Bleeding Disorders, Injectable Medication, Prescription Medications, and Dietary Requirements.

WHAT TO TAKE ALONG

Each passenger should have the name and phone numbers for his primary and specialist physicians. Also please carry with you in your carry-on luggage a copy of your latest medical records with such information as recent EKG,

continued on page 62

southpaw enterprises®
DAYTON, OHIO U.S.A.

Providing Hundreds of Sensory Integration and Development Product Solutions!

Therapists, educators, parents and physicians acknowledge Southpaw as the industry leader in providing high-quality, state-of-the-art and safe Sensory Integration and Developmental products. Our products are made to the strictest standards of quality. We also strive to make our products fun while providing you with the innovative and safe solutions you require for great therapy.

Phone toll free:
1-800-228-1698

Or contact us from our website:
www.southpawenterprises.com

Call for our FREE full line product catalog!

Southpaw Enterprises
P.O. Box 1047
Dayton, OH 45401-1047

Circle #70 or visit www.eparent.com/adinfo

The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW

- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made In U.S.A.

Circle #45 or visit www.eparent.com/adinfo

359 B

continued from page 61

medications list and allergies. A medical information sheet with next of kin, hospital and health and travel insurance information is also helpful. Also place in your carry on luggage your medications and spare eyeglasses or contacts and a small first aid kit. If you have a medical condition and you do not have a Medic Alert neck tag or bracelet, this would be a good time to purchase one and wear it. (Call Medic Alerts at 1-800-825-3785). It is also a good idea to have your travel agent's non-800 number if you are going to be out of the United States and need to call them.

WHAT TO LEAVE BEHIND

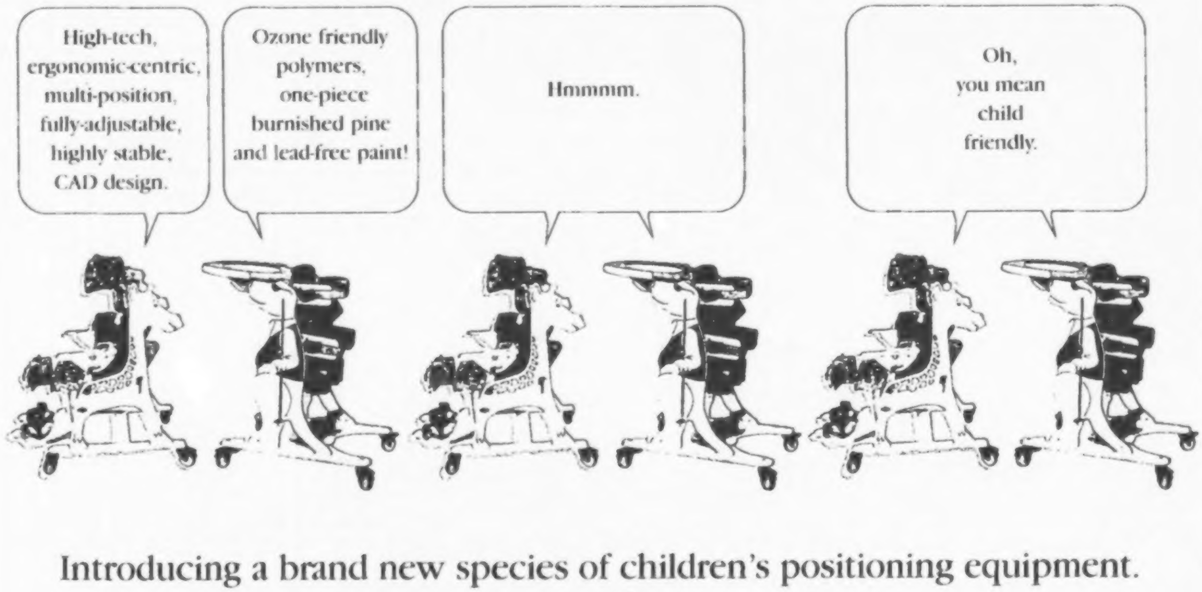
For your peace of mind make sure that you leave the following information behind for your friends and family: the name of the ship you as well as your flight information, your cabin number and reservation number, your travel agent's name and phone number and a photocopy of the first page of your passport. In your cruise documents you should find information for ship to shore phone numbers and the fax number to the ship. Do keep in mind that ships often can only receive faxes when they are at sea. In this case a copy of the ship's itinerary would be very helpful.

MEDICAL FACILITIES ABOARD SHIP

Many modern cruise ships come under the umbrella of the ICCL, which with the assistance of the American College of Emergency Physicians' section of Cruise Ship and Maritime Medicine, has developed a set of guidelines for the medical facilities on cruise ships. Their member lines have voluntarily agreed to support these guidelines. One of your questions as a passenger should be: "Is the cruise line I am considering a member of ICCL?" If not, you should investigate their medical capabilities before entrusting your well-being to them.

Medicare does NOT reimburse subscribers for medical care rendered on board ships unless the vessel is registered and flagged in the United States.

In the medical facility you will find one or more doctors along with highly skilled nurses. These dedicated professionals provide 24-hour coverage for health care needs. They have set office hours as well as a pager for instant notification of an emergency or urgent medical need. Please keep in mind that medical care is at the passenger's expense and that insurance assignment is rarely accepted on or off the ship. U.S.


High-tech, ergonomic-centric, multi-position, fully-adjustable, highly stable, CAD design.
Ozone friendly polymers, one-piece burnished pine and lead-free paint!
Hmmmm.
Oh, you mean child friendly.

Introducing a brand new species of children's positioning equipment.

JENX.
The perfect positioning. For body. And soul.

Distributed by BP BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #24 or visit www.eparent.com/ad info

Medicare does NOT reimburse subscribers for medical care rendered on board ships unless the vessel is registered and flagged in the United States.

Some facilities are state of the art and provide such things as telemedicine, digital X-rays and sophisticated laboratory diagnostics. But in all of them you will find basic life saving drugs and equipment for stabilization. When you are comparing a ship-based medical facility with a land-based one, it is important to remember that it is much more akin to a free-standing urgent care center than to a hospital. The shipboard medical facility does not have the luxuries of onboard specialists, large nursing staffs to offer 24-hour extended care, or highly specialized tests such as CAT scans. For these reasons if a patient requires ongoing medical care, it will be necessary for them to disembark at the first appropriate port of call for either care there or emergency air evacuation to an appropriate medical facility. Since any air evacuation will require several thousand dollars, it is imperative that passengers have insurance for this unexpected event.

LIFE BOAT DRILLS

Experienced as well as first time cruisers all too often endure lifeboat drills with only cursory attention. Saving your life in the rare event of a disaster will be up to you as well as the staff. Know the ways to your life boat station and what items to carry with you. Don't count on someone being at every turn to direct you; assume responsibility for your safety any time you set foot on a ship.

PREPARE AHEAD AND ENJOY YOUR CRUISE

Over 5 million Americans will cruise this year and only about 5% of them will seek medical attention from the ship's medical facility. The vast majority of the problems encountered will be minor and easily treated aboard ship. A few passengers, however, will suffer serious illness or injury that will require emergency treatment in the ship's medical facility and then medical evacuation to a shoreside hospital. In the unlikely event that you will require emergency treatment and/or evacuation, being properly prepared to assist the medical personnel with your history, emergency contact and travel insurance information will make your experience much less stressful. ■

Linda Allen, owner of Cruises by Linda Allen, is a Master Cruise Counselor who is also expert in disability access. Contact her by e-mail: lallen@cswnet.com. or phone: (800) 422-3445

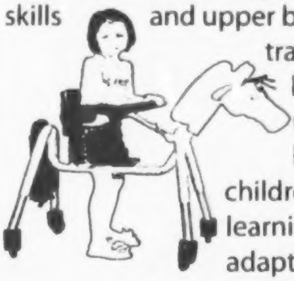
From OPEN WORLD, Vol. 2, Issue 4, Fall/Winter 1998/99. Copyright 1999. All rights reserved.

R.E.A.L. Design Introduces VIVO™
The New Multi-Therapy Pony

Children will love VIVO, the playful, spirited little pony with the head that bounces when moved and a colorful beaded tail. Parents and therapists will appreciate the valuable skills children gain by playing on VIVO because it functions as a balance rocker or gait trainer by simply interchanging the legs which snap on and off easily. As a rocking horse, VIVO promotes balance reaction skills and upper body postural development. As a gait trainer, it provides incentive for a child to learn ambulation skills. The soft upholstered seat back, with molded laterals, is height adjustable to position children comfortably and securely for rocking or learning to walk. Accessories are available for adapting VIVO to a child's positioning needs.

R.E.A.L. DESIGN 1.800.696.7041 Fax: 1.315.429.3071
www.realdesigninc.com

Circle #65 or visit www.eparent.com/ad info



UCP Research Fact Sheet
UNITED
CEREBRAL
PALSY
RESEARCH & EDUCATIONAL
FOUNDATION
Hope through research

HYPERBARIC OXYGEN THERAPY
In the Treatment of Brain Injury

REPORT OF A MEETING

On July 25-28, 2001, a meeting was held in which clinicians, clinical investigators and family members reviewed the present status of information about the use of hyperbaric oxygen therapy (HBOT) in the treatment of brain injury. Nearly all participants in the meeting were advocates of the use of HBOT; there were no presentations by conferees who were either opposed to the use of the therapy for this purpose or whose position was as yet undecided. One of the major topics of discussion was the recent report of the "Montreal trial" that demonstrated significant functional improvement in many of the cerebral palsy children participating in the randomized double-blind HBOT trial, but with no differences in functional outcomes in children treated either with 1.35 ATA of air or 1.75 ATA of 100% oxygen (see Research Fact Sheet: Hyperbaric Oxygen Therapy (HBO) for Children with Cerebral Palsy: Report of a Clinical Trial).

The conferees participated in two broad areas of discussion: (1) reports of clinical experiences that appeared to preserve life and restore impaired function when HBOT was administered soon after brain injury (e.g. traumatic brain injury; drowning; birth hypoxia; meningitis); and (2) the clinical experience that HBOT appeared to restore function in persons (usually children) with disabilities following brain injury at sometime in the past (e.g. cerebral palsy).

At this meeting, the principal presentations were reports of clinical experience utilizing HBOT, either individual cases or case series. The reports described functional improvement in both the acute and chronic situations following brain injury. In the chronic situation (cerebral palsy), the results of the use of 100% oxygen administered at a variety of atmospheric pressures were discussed (1.75 ATA; 1.5 ATA; 1.35 ATA); all were reported to be associated with positive short term and long term results; no reports were presented that described poor results. The recognized danger of hyperbaric oxygen was discussed (i.e. seizures), as were the less well recognized behavioral manifestations of oxygen toxicity (e.g. agitation; aggressiveness). In the experience of the conferees, it appears that these complications are unusual, but when they do occur they are manageable by the termination of therapy and the use later of lower levels of hyperbaric oxygen.

One focused item of conference discussion was the Montreal trial and the "implication" that the control subjects receiving air at 1.35 ATA were receiving a "placebo" (a non-therapeutic intervention). It was stated by clinical participants at the conference that air at 1.35 ATA increased both the oxygen level of red blood cells and caused oxygen in the air to dissolve in the blood's fluid (plasma); both increased the availability of oxygen to body tissues—including the brain.

It was proposed by several conferees that the control group of the subjects in the Montreal study were also receiving an increased oxygen supply to the brain; thus explaining the similar clinical improvement in both segments of the study population. If this is true, should air administered at 1.35 ATA be used instead of HBOT? The question was asked, but not answered.

In support of the effects of HBOT on the brain, a number of brain imaging studies using SPECT before and after treatment were presented. SPECT provides images of regional cerebral blood flow; by inference, a change in blood flow implies but does not demonstrate a change in cerebral metabolism. In all of the cases presented, SPECT showed increase in cerebral blood flow in a variety of poorly perfused areas of the brain following HBOT. It was hypothesized that these areas of increased blood flow were metabolically more active than prior to HBOT.

COMMENT:

The reports presented at this meeting of improved function and cerebral circulation cannot be disregarded by labeling them as "observations by biased advocates". These observations by skilled clinicians and parents need to be explored by appropriate scientific studies that meet the standards of modern research. One study, the Montreal study, clearly indicates that room air delivered at a low level of increased atmospheric pressure (1.35 ATA) gives identical results to 100% oxygen delivered at increased pressure (1.75 ATA). At this time, there is still no scientifically acceptable evidence that HBOT is useful in the treatment of disabilities associated with cerebral palsy. The following questions remain to be answered:

- Is HBOT (oxygen level? pressure level?) useful in the treatment of disabilities associated with cerebral palsy?
- Is hyperbaria alone (pressure level?) useful in the treatment of disabilities associated with cerebral palsy?
- Is oxygen supplementation alone (oxygen level?) useful in the treatment of disabilities associated with cerebral palsy?

Sufficient clinical experience does exist to support the need for additional controlled studies exploring these questions in a scientifically acceptable manner (i.e. randomized, double-blind trials). Air delivered in a hyperbaric chamber at 1.0 ATA can serve as a control.

Another issue also requires study: the suggestion that there are "idling" neurones in the brain years after injury that become active after the use of HBOT. At this time, there is no evidence that this is true. However, there are methods available to test this hypothesis: PET brain imaging or metabolic magnetic imaging. These quantitative methods of measuring focal brain metabolism can be applied before and after HBOT and will answer the question.

Are the above studies do-able? They are. To be successful they must have the active participation of the children to be studied, their caregivers, clinicians, and scientists. They also require the organizational arrangements and financial resources that these studies demand in order to be successful. The UCP Research & Educational Foundation is attempting to see if the necessary personnel, the organizational and the financial requirements can be mobilized to initiate these needed studies to evaluate the usefulness of HBOT in treating children with disabilities due to cerebral palsy. EP

International Symposium on Hyperbaric Oxygen in Cerebral Palsy and the Brain-Injured Child. Boca Raton, Florida; July 25-28, 2001. Richard A. Neubauer, MD, Chairman

PREPARED BY THE UCP RESEARCH & EDUCATIONAL FOUNDATION, WHICH HAS GIVEN PERMISSION FOR EP MAGAZINE TO REPRINT IT IN FULL.

© UCP RESEARCH & EDUCATIONAL FOUNDATION, AUGUST 2001.

Wenzelite Re/hab

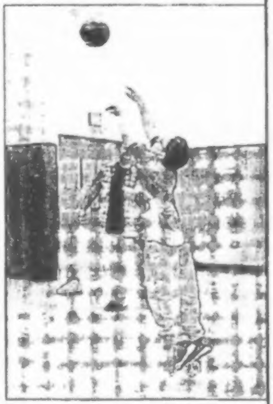
Providers of Pediatric Rehab Equipment

SEATING SYSTEMS
BATHING CHAIRS
STROLLERS
STANDERS
WALKERS

CALL US AT
718-768-8002 / (800) 706-9255
For information about our
FREE EVALUATION PROGRAM

www.wenzelite.com • e-mail: wenzelite@aol.com

Circle #81 or visit www.eparent.com/adinfo



REACHING UPWARD

AT THE EVERGREEN CENTER, we believe in learning as a means to personal independence. Combining school and community residence programs, The Evergreen Center creates an individual education program that helps each student become a part of the community.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631
Serving students with developmental, medical and behavioral needs since 1981.

Circle #41 or visit www.eparent.com/adinfo

On The Road To Orlando

GOLD SPONSOR: sigma-tau PHARMACEUTICALS, INC.

CONFERENCE SPONSOR: EP Foundation for Education, Inc.

SHOW PRODUCER: HAB H.A. BRUNO, LLC

IN ASSOCIATION WITH: EP Exceptional Parent

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD
WCD OR BUST!

WORLD CONGRESS
& EXPOSITION ON
DISABILITIES

OCTOBER 3 - 5, 2002

ORANGE COUNTY
CONVENTION CENTER
ORLANDO, FLORIDA

Employment Symposium
hosted by
Florida Division of Vocational Rehabilitation Services

MEDIA SPONSORS

Active Living magazine
Disabled Dealer of Southeast
EP (Exceptional Parent)
inMotion
New Mobility
PALAESTRA
Teaching Exceptional Children
Today's Caregiver
We Media

EDUCATIONAL SPONSORS

Allergan, Inc.
American Academy for Cerebral Palsy
& Developmental Medicine(AACPDM)
American Academy of Pediatrics
American Association for Active Lifestyles
& Fitness (AAALF)
Association of University Centers on Disabilities
Child Neurology Society
Dystonia Medical Research Foundation
National Institutes of Health
WE MOVE

SUPPORTING ORGANIZATIONS

AAMR
Amputee Coalition of America
Council for Exceptional Children
Easter Seals
Families of S.M.A.
Family Voices
Muscular Dystrophy Family Foundation
National Family Caregivers Association
National Multiple Sclerosis Society
National Parent Network on Disabilities
National Perinatal Association
Southeast Disability & Business Technical
Assistance Center
Special Olympics
Spina Bifida Association of America
TASH
UCP
U.S. Disabled Athletes Fund

(877) 923-3976 x832 ◆ wcdinfo@wcdexpo.com ◆ www.wcdexpo.co

Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—October 3 - 5, 2002
LOCATION:
Orange County Convention Center—Orlando, Florida

A UNIQUE GATHERING—A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract **physicians ○ families ○ direct support professionals ○ people with disabilities ○ allied health care professionals ○ educators ○ adapted physical education specialists.**

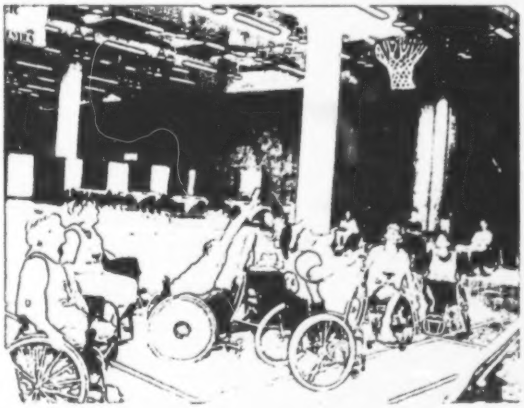
TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.

SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more.

EMPLOYMENT SYMPOSIUM PAVILION: Human resource managers will discuss career opportunities.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.



CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment.

- All WCD attendees can experience discussions by internationally renowned experts specializing in neurology, orthopedics, pediatrics, internal medicine, family medicine, physical medicine, epidemiology, DDS, movement disorders, mitochondrial and metabolic disorders, neonatology, seizure disorders, autism, and other disabilities and chronic conditions as well as general practitioners.
- CME and CEU accreditation will be provided through approved accreditation institutions.
- Hear parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.
- An Employment Symposium produced in conjunction with the Florida Department of Education, Division of Vocational Rehabilitation Services will offer sessions for people with disabilities, their families and employers.
- Learn from special education professionals what is going on in classroom environments.
- Participate in adapted physical education activities and seminars.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

October 3-5, 2002 ○ WORLD CONGRESS & EXPOSITION ON DISABILITIES

Sigma-Tau Pharmaceuticals

Pairing Scientific Research with Compassion

Sigma-Tau Pharmaceuticals, Inc. has proudly agreed to participate in the 2002 World Congress & Exposition on Disabilities as a gold sponsor. We feel that this sponsorship is one of many examples of Sigma-Tau's adage that no patient should ever be overlooked, no matter how rare his or her disorder.

Sigma-Tau Pharmaceuticals specializes in treatments for rare disorders and underserved medical needs through its manufacture of orphan drugs—medications with treatment populations of fewer than 200,000 patients.

Orphan drugs generally aren't highly profitable. Most are a break-even business opportunity at best. Their discovery in most cases, won't cause stock prices to skyrocket. However, orphan drugs do save lives and improve the lives of people with these rare conditions. They can make life worth living for people with diseases few people recognize.

Sigma-Tau devotes up to 20% of its revenue—a rate that exceeds the industry average—to clinical research in the U.S. and Europe. Sigma-Tau Pharmaceuticals produces Carnitor® (levocarnitine), a prescription form of levocarnitine available for the treatment of carnitine deficiency in metabolic disorders. Carnitor Injection is the only FDA approved treatment for carnitine deficiency in End Stage Renal Disease patients. Levocarnitine is a natural occurring amino acid derivative that helps the body convert food into energy, the process called metabolism. We get most of the carnitine we need—about 75%—from the foods we eat, especially from red meat and dairy products; we produce the remaining 25% ourselves. Levocarnitine works by carrying fats and other nutrients to structures within our cells, called mitochondria, and by clearing toxic waste from those cells. Without enough levocarnitine, our cells become starved of the nutrients they need to function properly and become overloaded with toxic waste. The results can be devastating. For some patients, carnitine deficiency can be life threatening. Several factors can cause carnitine deficiency: genetic defects, poor diet, or even the treatments for certain other disorders, including epilepsy treatments and kidney dialysis.

In addition to educating physicians, families and patients about Carnitor, Sigma-Tau Pharmaceuticals is an active participant in its community. As a member of the Community Volunteer Corporation of Montgomery County, Maryland, the company enjoys organizing and participating in events such as Christmas in April, supporting local food shelters and families, and Toys for Tots. "The employees at Sigma-Tau Pharmaceuticals realize the importance of giving back to our community and that not everyone is as fortunate as we are," says Justina Lambert, Vice President of Corporate Affairs.

For more information on Sigma-Tau Pharmaceuticals or Carnitor, please visit their Web site www.sigmatau.com or call 1-800-447-0169.

Virtual WCD

www.vwcdexpo.com

☐ View the latest products and services
☐ Read updated news items
☐ Communicate with people in the disability community
☐ Use the comprehensive bulletin board

October 3-5, 2002 ◦ WORLD CONGRESS & EXPOSITION ON DISABILITIES

Attending the WCD is like going back to college: I acquired so much knowledge, interacted with a diverse population, and had a difficult time choosing which "classes" to take.

Amanda McIntire, Inclusion Coordinator
Child Care Resource Network
Daytona Beach, FL

I enjoyed the variety of topics, the inclusion and collaboration of different disciplines, the inclusion of parents and families, the inclusion of individuals with disabilities and the sports and activities in the Expo Center. Please keep up the good work!

Sharon Tifany Bowers
Texas Woman's University
Denton, TX

The WCD Conference and Exposition allowed me to network with others who understand the challenges associated with living with a disability. Thank you WCD Planners!

Lynnie Morgan, Volunteer and Parent of Challenged Children, Canine Companions for Independence
Concord, CA

This was a totally inclusive event for a totally inclusive audience!

Camille Anders, Executive Director
Aldersgate Homes, Inc.
Atlanta, GA

"That event (the World Congress & Exposition on Disabilities) was magnificent. You have a subgroup, a session, for every subject under the sun. It's the most comprehensive educational program I've ever seen in any one setting."

—Governor Jeb Bush

The exhibits provided a great deal and wide variety of helpful information and were the best part of the event.

Jennifer Ways, Physical Therapist
Longview School,
Montogomery County Public Schools
Gaithersburg, MD

Please send me information on the World Congress & Exposition on Disabilities, October 3-5, 2002

I AM INTERESTED IN: ☐ Exhibiting at the Show ☐ Attending the Show

Name

Company

Address

City State Zip Code

Telephone Fax

Email

Send Me Information:
877-923-3976, x832
Fax this page to:
201-226-1236
Mail this page back to:
WCD
210 Route 4 East
Suite 403
Paramus, NJ 07652
Email your request from:
www.wcdexpo.com

For complete details, visit our website at www.wcdexpo.com, or call: (877) 923-3976 ◦ (201) 226-1446

EP3/02

SARAH SYNDROME:

A Mother's View of Having a Child with No Diagnosis

by Jennifer Frost

Despite the more than 6000 known rare diseases, it is still common to hear from parents that their child is either "yet to be diagnosed" or has "no known diagnosis." There is a difference, of course, and it has nothing to do with the diagnostic acumen of the attending clinicians.

For many parents, hearing "what their child has" is the beginning and the end—the end of their turmoil, their hunt, their fears and their hope. But for many, the definitive diagnosis demarcates the beginning. They hunt for the noted researchers, clinics, schools, treatments, support groups, and publications about fragile X, Down syndrome, Edwards syndrome, or cri du chat. But the issuance or utterance of a "diagnosis" can also throw the parents into an abyss. The "diagnosis" of cerebral palsy, autism or developmental delay can require a Herculean effort to sort through the spectrum, horizons, borders, variants and atypicalities these conditions represent.

SARAH AND HER MOM

For the parents of children with an unspecified diagnosis there are no expectations. With no expectations, a new and evolving partnership can flourish, a partnership between the parents and the professionals not unlike a person with blindness and the guide dog. They are analogous because the parents and the professionals take turns in wearing the harness and playing the guide. Together they can navigate to a distant point without the often-complicating array of facts and case studies available in "unquestioning conditions."

EP Magazine receives thousands of letters each year from parents "wanting to know" or asking "does anyone else have a child with what my kid has?" The need to belong is so strong in our psyches that even in the realm of disabilities our desire to connect is powerful. Anthropologists know the power of tribe, clan and community and refer to it as "social cohesion."

Parents of children with special needs, regardless of the name or namelessness of their condition, share so much, providing an instantaneous bond among them. When it comes to sharing information, experiences, tips and dead-ends, the one common criterion that seems to make the most impact is: Patient presents with a couple of exceptional parents in tow.

—Rick Rader, MD, Editor-in-Chief

We were a young married couple who just wanted to share their love with children. After two years, we had our first daughter, Hannah. She was perfect in every way, normal and healthy. On April 20, 1999, just 17 months later, our second child, Sarah Elizabeth, was born. We had no reason to believe that she wouldn't be every bit as perfect as Hannah.

I was admitted to the hospital the night before for an induction because of a low level of amniotic fluid. Things happened fast and I knew something was wrong. It was too late for a caesarean section and Sarah was born OT ("occiput transverse," or face sideways instead of face down) with the aid of an episiotomy and vacuum extraction. I had no idea at the time how dangerous this was, nor were these dangers conveyed to me. Sarah received a small amount of oxygen and some X-rays of the extensive bruising, but after an extra day in the hospital, we went home together. There was no way of knowing that the damage was already done.

As a second-time mother with a background in early childhood development, I knew within weeks that something was wrong. Sarah never wanted to be held, not even for comfort. She had poor sucking reflex that, at the time, appeared to be just a "slow start." She held her head to only one side and kept her body tightly rolled into a ball. Within the first few months, doctors discovered that she had bladder reflux, and began preventive antibiotics that she continues today. Unfortunately, this didn't explain her lack of development.

When Sarah was five months old, her pediatrician referred us to a pediatric neurologist, a pediatric ophthalmologist, and to the Siskin Children's Institute for Therapy and Family Training. It was at this time I was introduced to TEIS (Tennessee Early Intervention System.) TEIS is a state-funded early intervention program for children of any economic status with special needs.

During her first assessment under TEIS and Siskin, we learned that Sarah had global developmental delay. It did not come as a surprise, because at seven months old, she could not roll from side to side, hold her head up or do anything else that a baby of that age could do. She had a normal cry, but did not coo or babble at all. Sarah immediately began weekly therapy and we had family training sessions at Siskin.

We remained at Siskin for the next two years. While we are very thankful for the treatment she received there, this past June we chose to discontinue family training. I was not prepared to put Sarah in a school program, so Sarah continued her physical therapy at our area Children's Hospital.

Sarah's first appointment with her neurologist carried many surprises. His evaluation revealed hypotonia and very poor underdeveloped reflexes, but he wasn't sure why. An MRI of her brain and cervical spine were clear. Blood and urine tests were performed to rule out metabolic and chromosomal disorders, diseases or syndromes. All tests were negative, which was great news. However, we still had no answers. Her traumatic birth was always mentioned, but not considered much. The doctors seemed to think that Sarah could have been very ill at birth, and that her significant health problems are birth-related.

After several follow up visits, her neurologist began to change his opinion. He said that there is a handful of kids out there with developmental delay and no diagnosis. He

---

EP selects "parent editorials" for the purpose of providing a forum for emerging opinions and evolving parenting philosophies. EP also welcomes responses to previous editorials that represent divergent views. These select editorials do not necessarily reflect the opinion of EP. — Rick Rader, MD, Editor-in-Chief

Parents may send their submissions for Parent Perspective to Exceptional Parent Magazine, 65 E. Route 4, River Edge, NJ 07661; e-mail: epedit@aol.com. All submissions are subject to review and editing by EP.

368

went on to say that these kids can fit under the large umbrella of CP, but he preferred not to classify Sarah under cerebral palsy just because we needed a diagnosis. The general opinion is that Sarah had a bleed deep in her brain during delivery, but we don't know where and we don't know what to expect. Sarah continues to see her neurologist once a year for monitoring, but there's just nothing he can do for her.

Sarah is now 2 years old, but still cannot get into a full sitting position. She can only sit for short periods of time without falling. She cannot crawl, stand, walk or talk. Sarah has just received her first wheelchair, and we hope to receive her first power wheelchair soon. What a world there is for her to see! Until now, she pivoted and rolled to move around. Sarah has also begun an assistive technology program that we hope will improve her ability to communicate. She is thriving and learning like never before and we are very excited about her future.

There have been lots of tears and sleepless nights, uncertainties and immeasurable heartache. Yet nothing can equal the joy that Sarah has brought to my life. Her smile speaks volumes and her eyes lead my heart. I can honestly say that she touches the lives of everyone she meets. To know her is to love her. Although she may not be "normal," she is certainly perfect, and worthy of every effort to improve her quality of life. When I tire of the endless rounds of doctors, therapists, hospitals, schools and tests, I remember that Sarah and I are not alone. There are thousands of children with special needs all over the world and each one of them is worthy of the efforts that parents, caregivers, doctors, researchers, therapists, schools, hospitals and legislatures can make to improve their lives.

It doesn't matter that I cannot join a support group for a specific syndrome, or join a national organization for diseases or disorders. In the end, whether a child with special needs has a diagnosis or not, the challenges are the same. As parents or caregivers of these children, it is important for us to remember that they are gifts from God. All have a purpose and a plan in His will. My faith has definitely been tested, but my trust and hope remain in God. I feel that it is my greatest duty in life to be a mother, and I am honored that God gave me Hannah and Sarah.

As a parent, I would like to suggest this for professionals:

- Don't try to have all the answers; no one has all the answers;
- Prepare parents with honesty, not hope;
- Expect a broad range of emotions;
- Care enough to be informed about the special needs community;
- Listen to what the parent is saying and understand that you don't know how the parent feels. EP

Jennifer Frost and her family make their home in Sales Creek, Tennessee.

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.
Scooters and chairs that won't fit in other vans can fit in a Kneelvan.
KneelVan
Kneelvan is the most reliable lowered floor minivan ever.
More ground clearance than any other lowered floor minivan.
Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel**. Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #44 or visit www.eparent.com/ad info

familiar faces

SHELBY ANN

Pictured is **Shelby Ann Maloy**,9, and her Elmos. Shelby has lissencephaly syndrome and seizures. She attends physical and occupational therapy. She loves her big sister Kelsey, who is 14 years old. Shelby lives with her parents, James and Trish.

ADAM

Adam J. Gunhammer, 6, is a special boy. He gets around with a wheelchair and his walker. He loves musical toys, going to school, eating, and his grandmother, who spends a lot of time with him. They work on little projects together every day. She is very proud of him.

SCOTTY

Scotty Jones, 10, enjoys cartoons, noisy toys, and his puppy Angus. Scotty has cerebral palsy as a result of shaken baby syndrome. He is non-verbal and non-ambulatory. He helps out with Toys for Tots every year.

JOSE

Jose M. Navarro, 2, loves to stroll along the beach! He also loves to play with his sisters Amanda, 10, and Victoria, 1. Jose has Down syndrome. He loves to greet people and to make new friends He lives with his parents, Jose and Barbara, his sisters, and his dog Midnight.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (Exceptional Parent), 65 E. Route 4, River Edge, NJ 07661. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

CARES Foundation, Inc.

by Kelly R. Leight

CARES (Congenital Adrenal hyperplasia Research, Education and Support) Foundation, Inc. is a non-profit, educational organization. Its purpose is to educate the public and physicians about all forms of congenital adrenal hyperplasia (CAH), its symptoms, diagnostic protocols, treatment, genetic frequency, the necessity for early intervention and benefits of newborn screening. It is also dedicated to providing support and information to affected individuals and their families.

Congenital adrenal hyperplasia (CAH) is a family of inherited disorders affecting the adrenal gland. The most common form is 21-hydroxylase deficiency, which is inherited in severe or mild forms. The severe form, called classical CAH, is usually detected in the newborn period or in early childhood. The genetic frequency of classical CAH is approximately 1 in 15,000 births. The milder form, called non-classical CAH (NCCAH), may cause symptoms at anytime from infancy through adulthood. Non-classical CAH is a much more common disorder than classical CAH. It affects 1 in 100 in the general population of New York City and is most common in certain ethnic groups. It affects 1 in 27 Ashkenazi Jews, 1 in 40 Hispanics, 1 in 53 Croatians, and 1 in 300 Italians. This frequency makes NCCAH the most frequent genetic disorder identified to date.

CAH and NCCAH are autosomal recessive genetic disorders. Scientists have pinpointed the location of the group of genes that causes CAH to chromosome 6. DNA testing is now available for diagnosis of CAH and NCCAH and to detect carriers of the gene mutations.

This particular group of genes contains instructions that the adrenal glands (which are located on top of the kidneys) need in order to produce a certain enzyme (21-hydroxylase). Without this enzyme, the adrenal glands are unable to synthesize cortisol, a hormone necessary for life, in physiologically sufficient amounts. To compensate for this, the pituitary gland in the brain stimulates the adrenal gland to produce more steroid precursors. As a result, however, androgens (masculizing steroid hormones) are produced in excessive amounts. In addition, more than 75 percent of all babies with classical CAH lack another adrenal hormone, aldosterone, which regulates sodium and potassium, necessary for maintaining normal fluid volume of the body. These babies become very ill soon after birth if not diag-

continued on page 74

Caring for the Most Vulnerable

One mother's search for information on her daughter's disability uncovers a dire need.

Kelly R. Leight, executive director and founder of CARES Foundation, Inc., shares her story

"When my 7-year-old daughter, Alyssa, was diagnosed with non-classical congenital adrenal hyperplasia in February 2000, I was worried, shocked and upset. I wanted support, and I wanted information. Naturally, I went to the Internet to find answers. I was surprised to find that there was no organization specifically dedicated to CAH or much in the way of support for families going through the difficulties of dealing with and understanding this disorder. Some information was out there if you searched hard enough, but there was no centralized resource. I wanted to create a centralized source of information on the Internet, as well as provide support services to the CAH community.

Alyssa Leight

"At the same time, I became aware of how little the non-endocrine medical community knew about both classical and non-classical CAH. I became concerned about a trend toward characterizing symptoms of early puberty, often the first sign of non-classical CAH in children, as normal or benign. If further tests were not conducted on my daughter and a referral made to a pediatric endocrinologist, my daughter would have gone undiagnosed and suffered irreparable harm. I wanted to help publicize the danger in promoting this myth of early puberty, as well as to educate the public, the ethnic groups most affected, and the medical community about the signs, symptoms and genetic frequency of non-classical CAH.

"I also learned of the life-saving benefits of newborn screening for CAH. At the time, I was surprised to find that my own state, New Jersey, did not screen for CAH at birth, but many others did. I went on a quest to get the state to add CAH to its screening program in addition to bringing its newborn screening services to include all other diseases that can be screened for at birth. The effort paid off, and now New Jersey mandates newborn screening for more disorders than any other state. I hope to encourage other parents and affected individuals to get involved in newborn screening advocacy."

HDIS

Convenient Home Delivery of Bladder Control Products

Try our Attends® Youth Brief, FREE!

Reliable protection that fits like regular underwear!

FREE *Sample Offer!*

- Ideal for children weighing 35 to 75 pounds.
- Four refastenable tapes provide an adjustable fit.
- Stay-Dry lining keeps moisture away from the skin.
- Wetness indicator lets you know when the brief needs to be changed.

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

Call now for a FREE sample!
1-800-2MY-HOME®
(1-800-269-4663)

"We're happy to answer any questions you have."
- Mary

©2002, HDIS 024-127

Circle #46 or visit www.eparent.com/adinfo

The Many Faces of Matheny.

A lifetime of caring for people with developmental disabilities.

Award-winning programs for children and adults in medicine and education
- Residential
- Outpatient
- Home Health

As an affiliate of major universities and hospitals, Matheny shares its expertise with the medical community.

MATHENY
School and Hospital
Main Street, P.O. Box 339
Peapack, NJ 07977
908.234.0011
www.matheny.org

Circle #58 or visit www.eparent.com/adinfo

continued from page 73

nosed and treated promptly. The remaining 25 percent, who produce sufficient aldosterone, are called "simple virilizers."

Classical CAH

Salt-wasting classical CAH must be detected at birth to avoid adrenal crisis, which can lead to death. Infant females generally come to medical attention because the disorder causes affected females to exhibit recognizable genital abnormalities. The clitoris is usually enlarged, and may even look like a small penis, and the labial folds may be joined to resemble the scrotum. Sometimes, if the extent of ambiguity is great, the female baby may be misidentified as a male. These abnormalities are only external. The female reproductive internal organs are not affected and are intact. Male babies with CAH appear normal at birth. Newborn males show no other outward signs of the disorder and are sent home without treatment. These babies sometimes present for urgent medical attention at a time when they are beyond resuscitation.

Because the condition is life-threatening if not treated soon after birth, many states require newborns to be screened for classical CAH. Currently, less than half of our states screen newborns for CAH as part of routine newborn screening testing. CARES Foundation, Inc. is working to expand newborn screening for CAH.

Non-classical CAH (NCCAH), is much more common than classical CAH. A study of New York residents found it affected 1 in 100 people. But—perhaps because it is less severe and harder to recognize than the classical form of the disease—NCCAH has not received the attention it deserves as a widespread condition that affects health and quality of life.

NCCAH is a variation of CAH that: can begin at any time from early childhood to early adulthood; is not immediately life-threatening; has a range of symptoms which overlap with other disorders and therefore may not be easily diagnosed; is less likely to be diagnosed promptly.

Girls born with NCCAH have normal genitals. Boys also appear normal. Because the symptoms begin later in life, NCCAH is sometimes called late-onset CAH, adult-onset CAH, or the attenuated form of CAH.

Symptoms of NCCAH

NCCAH symptoms vary from person to person; in addition one person's symptoms may come and go over time. They can begin at any time in life, but frequently start in early childhood. These symptoms are often mistaken for premature puberty in girls this is before age 8 and boys before 9.

BOTH MALES AND FEMALES WITH NCCAH MAY SHOW THE FOLLOWING:

- Premature development of body hair (pubic and underarm);
- Body odor (young children's perspiration normally has no odor);
- Early, rapid growth spurt, but ultimately short stature as adult;
- Oily hair and skin;
- Severe acne;
- Anxiety, depression, mood swings, migraines;
- Infertility;

SYMPTOMS IN GIRLS AND WOMEN:

- Early age of first menstrual period;
- Menstrual irregularities;
- Baldness, especially at the temples (male pattern baldness);
- Excessive hair growth; facial hair on chin and upper lip may be thick, coarse, and

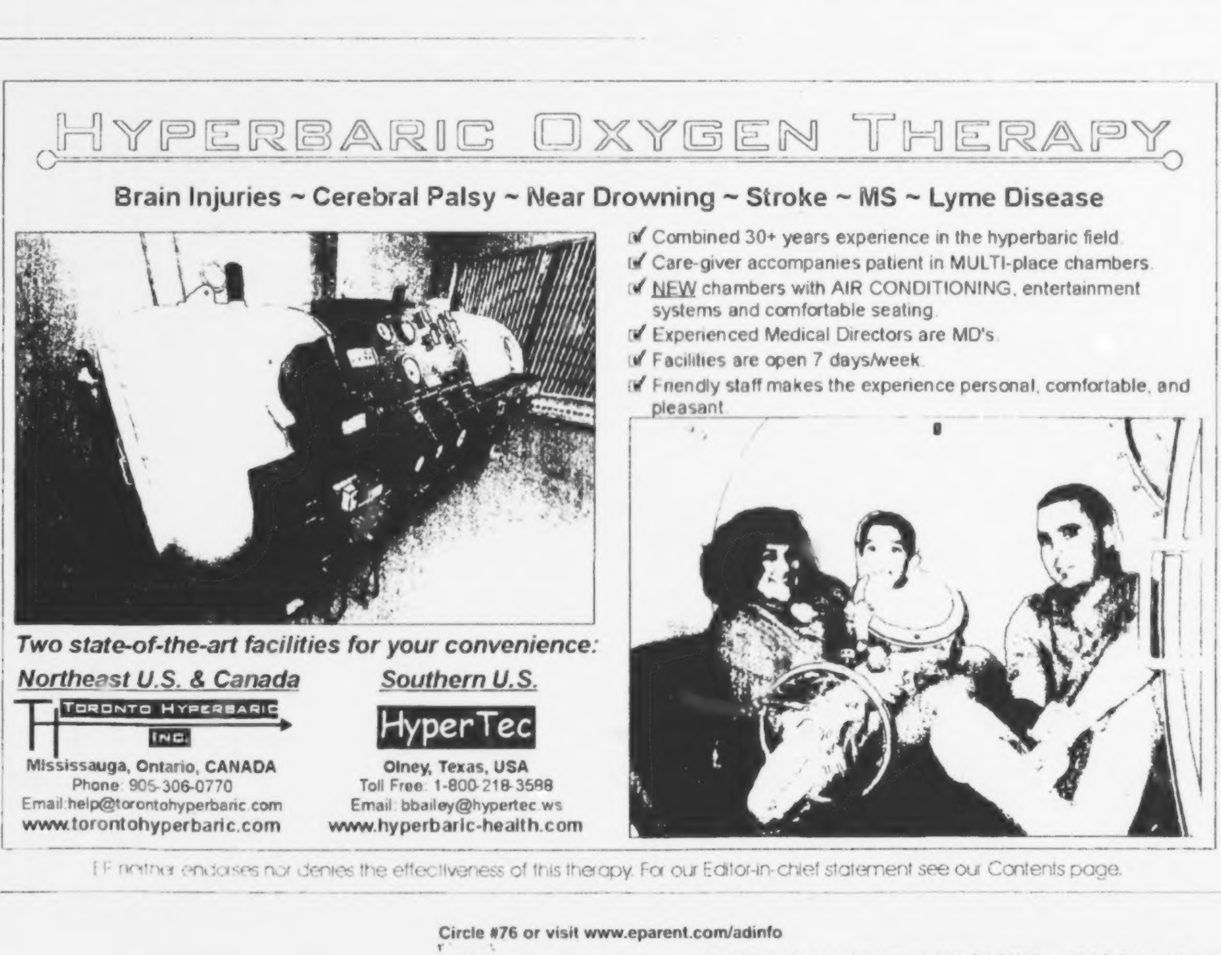
continued on page 76

Getting Action

HEALT
ospit.: • Ove
Ridge • Th

Acting Governor Donald T. DiFrancesco (pictured at right with Kelly Leight and her daughter, Alyssa) announced in April 2001 that New Jersey will expand its statewide system of newborn testing to include 14 disorders which, if not caught early, can cause severe health problems, mental retardation and even death. In July, the state added newborn screening for biotinidase deficiency, congenital adrenal hyperplasia (CAH), cystic fibrosis, and maple syrup urine disease. In January 2002, six more tests were added for the fatty acid oxidation disorders (MCAD, SCAD, LCAD and VLCAD) and two urea cycle disorders, arginosuccinic acidemia and citrullinemia.

For more information on the New Jersey decision, the report of the Newborn Screening Advisory Panel is available on the Department of Health and Senior Services web site at http://www.state.nj.us/health.


HYPERBARIC OXYGEN THERAPY

Brain Injuries ~ Cerebral Palsy ~ Near Drowning ~ Stroke ~ MS ~ Lyme Disease

☑ Combined 30+ years experience in the hyperbaric field.
☑ Care-giver accompanies patient in MULTI-place chambers.
☑ NEW chambers with AIR CONDITIONING, entertainment systems and comfortable seating.
☑ Experienced Medical Directors are MD's.
☑ Facilities are open 7 days/week.
☑ Friendly staff makes the experience personal, comfortable, and pleasant.

Two state-of-the-art facilities for your convenience:

Northeast U.S. & Canada
TORONTO HYPERBARIC INC.
Mississauga, Ontario, CANADA
Phone: 905-306-0770
Email: help@torontohyperbaric.com
www.torontohyperbaric.com

Southern U.S.
HyperTec
Olney, Texas, USA
Toll Free: 1-800-218-3588
Email: bbailey@hypertec.ws
www.hyperbaric-health.com

EF neither endorses nor denies the effectiveness of this therapy. For our Editor-in-chief statement see our Contents page.

Circle #76 or visit www.eparent.com/adinfo

continued from page 75

dark; • Polycystic ovary syndrome (PCOS);

IN MALES, NCCAH CAN ALSO PRODUCE:

- Early beard growth;
- Enlarged penis with comparatively small testes;
- Low sperm count;
- Short stature

If these symptoms are present, it's important to consult a board-certified pediatric endocrinologist or adult endocrinologist.

Treatment of NCCAH

With proper treatment, the outlook for a healthy life with NCCAH is excellent. NCCAH is treatable with oral glucocorticoids. A board-certified pediatric endocrinologist will be able to judge whether to add additional medications, such as a gonadotropin-releasing hormone analog to inhibit brain stimulation of the adrenal production of steroids.

New Developments in Treatment and Research on CAH and NCCAH

CARES Foundation, Inc.'s medical advisor, Maria I. New, MD, professor and chair, Department of Pediatrics and chief of the Division of Pediatric Endocrinology at New York Presbyterian Hospital-Weill Cornell Medical Center is currently conducting research into possible gene therapy to treat CAH and NCCAH. This is one of the most promising developments in finding a cure for this disease.

NeoGen Screening, Inc., a leader in developing and refining techniques used to detect inherited diseases in the newborn and a private provider of newborn screening services, has received a research grant from NIH to refine screening techniques for CAH. Current screening reliably picks up only babies with the salt-wasting form of CAH. This grant will expand the sensitivity of the testing to include detecting the non-classicals as well. **EP**

For more information, contact
CARES Foundation, Inc.,
PO Box 264
Short Hills, NJ 07078-0264
(973) 912-3895 or
(866) 227-3737 (toll free)
e-mail: kelly@caresfoundation.org;
Web site:
http://www.caresfoundation.org

Kelly R. Leight is an attorney and the mother of Joshua and Alyssa. In addition to her work with the CARES Foundation, she has been an active advocate in many other organizations. Ms. Leight serves as a Commissioner on the New Jersey Catastrophic Illness in Children Relief Fund Commission. She is also a founder and spokeswoman for 4 Our Families, a statewide political action committee on issues of importance to NJ women and their families.

RIDE THE LIGHTNING!
PRO LACROSSE AT CONTINENTAL AIRLINES ARENA
A JAYSON WILLIAMS PRODUCTION

STORM NEW JERSEY

Upcoming Home Game Schedule:

Sat Mar 16 Ottawa 8:00pm
Sat Mar 23 Columbus 7:30pm

www.njstorm.com • 1.866.NJSTORM

Circle #61 or visit www.eparent.com/adinfo

6.8

FOCUS ON PEDIATRIC MOVEMENT DISORDERS:

MYOCLONUS

By Terence D. Sanger, MD, PhD
with Joy E. Bartnett, NASW, AMIA, AMWA

Most people take for granted their ability to control their body movement. We *will* ourselves to move—walk across a room, sit in a chair or simply remain still. For millions of children, however, these simple, everyday acts are frustratingly difficult, if not impossible. These children are living with neurologic movement disorders.

The major neurologic movement disorders that may affect children include ataxia, bradykinesia, choreoathetosis, dystonia, myoclonus, spasticity, tics, and tremor. This article, the second in a series on pediatric movement disorders, offers timely information on the definition, causes, evaluation, diagnosis and treatment of myoclonus.

WHAT IS MYOCLONUS?

Myoclonus is a neurologic movement disorder characterized by sudden, quick, jerky, involuntary movements. These movements are usually extremely rapid or lightning-like. An attempted voluntary movement, a sensory stimulation or a sudden startle may trigger them, or they may occur continuously. Myoclonus may be observed as occurring rhythmically (as in myoclonic tremor) always affecting the same body parts or moving throughout the body. The condition may occur in the neck, back, face, a single limb or the entire body. If the symptoms of myoclonus are severe, children may lose their grip on objects, involuntarily throw objects, lose their balance or fall over.

There are many different causes, but in general, myoclonus occurs when a part of the brain or spinal cord is irritated or injured. Irritation may take the form of physical pressure (such as a tumor or local inflammation) or a chemical irritation because of toxins or other abnormal chemicals in the brain. While myoclonus in adults can be caused by a variety of minor and treatable problems, myoclonus in children often signals the presence of a more serious problem. For this reason, it is extremely important that children with myoclonus undergo a thorough evaluation for tumors, toxins, chemical imbalance and a variety of different diseases.

In some children, myoclonus is severely disabling, particularly when an attempted voluntary movement triggers myoclonic activity. In other children, the symptoms are relatively mild.

THERE ARE MANY DIFFERENT FORMS OF MYOCLONUS, INCLUDING:

- **Sleep myoclonus** is a normal and common form of mild myoclonus. It occurs frequently in both children and adults. Individuals with this form of myoclonus experience occasional brief jerking movements of an arm or a leg while falling asleep.
- **Negative myoclonus**, also known as asterixis, is characterized by a sudden involuntary relaxation, rather than contraction, of a muscle.
- **Action myoclonus** is triggered or worsened by attempts at movement.
- **Polymyoclonus** causes myoclonic jerks that can occur randomly throughout the body.

MYOCLONUS IS FREQUENTLY ASSOCIATED WITH EPILEPSY:

- **Epilepsia partialis continua** is a type of focal epilepsy that causes myoclonic tremor.
- **Progressive myoclonus epilepsies**; or PMEs, are a specific group of degenerative disorders in which the association of myoclonus and epilepsy is common.

The frequent association of myoclonus and seizure disorders suggests that there may be a common cause for myoclonus and certain types of epilepsy. Epilepsy, sometimes referred to as a "seizure disorder," is a neurological disorder characterized by episodes of abnormal electrical activities within the brain. These episodes typically cause seizures that affect awareness, movement or sensation.

UNDERLYING MECHANISMS IN THE CENTRAL NERVOUS SYSTEM RESPONSIBLE FOR MYOCLONUS

The precise nature of the underlying mechanism(s) responsible for the development of myoclonus is not fully understood. Myoclonus may be categorized according to the most likely source of these movements within the central nervous system. These include:

- **Cortical myoclonus** – originating in the outer layer of the brain or cerebral cortex;
- **Subcortical myoclonus** – originating within deep portions of the brain or brainstem and
- **Spinal myoclonus** – originating within the spinal cord.

Cortical myoclonus is possibly a result of lack of control within the brain's sensory or motor cortex; however, the reason is not known. Subcortical myoclonus is often caused by abnormalities in the brainstem. Spinal myoclonus is presumed to stem from abnormalities in certain spinal inhibitory circuits.

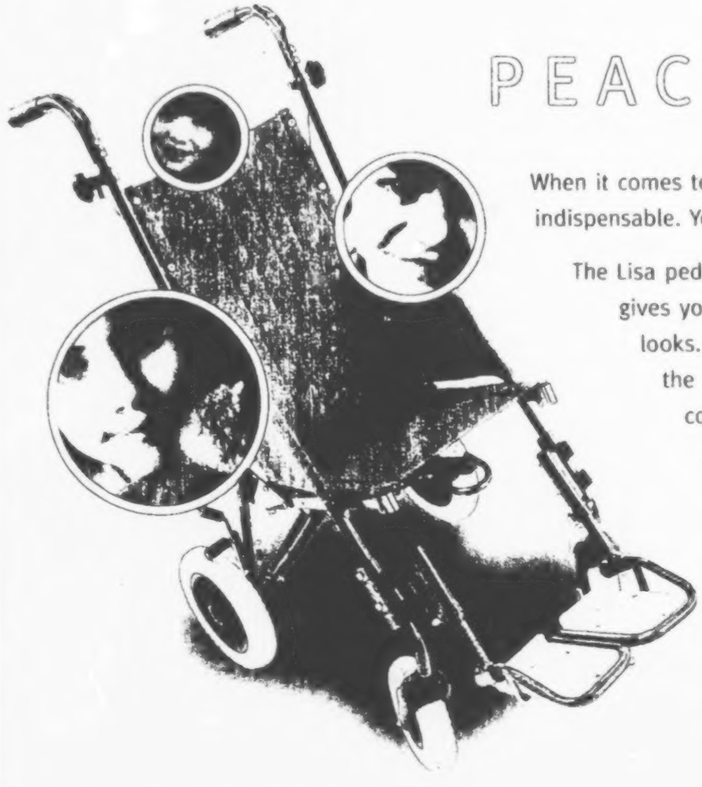
Another distinct group of disorders associated with myoclonic movements is known as startle syndromes. These disorders, which are characterized by explosive, jerking movement in response to environmental

continued on page 79

Ask the Doctor addresses issues of concern to our readers. Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products. Send questions to: Ask the Doctor, Exceptional Parent, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com.

WHAT ARE THE VARIOUS FORMS OF MYOCLONUS AND WHAT ARE THEIR UNDERLYING CAUSES? Myoclonus and its various forms include:

- Physiological myoclonus including normal sleep myoclonus and benign myoclonus of infancy;
- Essential myoclonus including familial essential myoclonus, essential myoclonus-dystonia, and stimulus-sensitive myoclonus;
- Epileptic myoclonus including juvenile myoclonic epilepsy, progressive myoclonic epilepsies (PME), epilepsia partialis continua, Rasmussen's encephalitis, early infantile myoclonic encephalopathy, infantile spasms (also known as West syndrome), Lennox-Gastaut syndrome, benign familial myoclonic epilepsy, and Angelman syndrome; and
- Symptomatic myoclonus, including:
  - fixed injuries such as carbon-monoxide poisoning, hypoxic injury or near-drowning (Lance-Adams syndrome), heatstroke, trauma, stroke, or electrocution;
  - storage or degenerative myoclonus such as sialidoses (cherry-red-spot-myoclonus); lipidoses; lysosomal storage diseases (e.g., Niemann-Pick type C, Tay-Sachs, Sandhoff's); other storage disorders (neuronal ceroid lipofuscinosis, neuronal brain iron accumulation type 1, Wilson's disease, Lafora body disease); Baltic myoclonus; spinocerebellar ataxias or SCAs; dentatorubropallidoluysian atrophy (DRPLA); multiple sclerosis; and certain mitochondrial disorders;
  - Infectious or parainfectious myoclonus, such as new-variant Creutzfeldt-Jacob disease (nvCJD); subacute sclerosing panencephalitis (SSPE); viral encephalitis; and streptococcal infections;
  - Endocrine-based myoclonus such as myoclonus associated with hyperthyroidism, hyponatremia, or hypoglycemia;
  - Structural myoclonus including tumors that irritate the brain in a direct manner, tumors that release chemicals into the blood (as in abdominal or thoracic neuroblastoma, which causes the opsoclonus-myoclonus-ataxia syndrome), palatal myoclonus (with injury to the Guillain-Mollaret triangle in the brainstem and cerebellum);
  - Drug- or toxin-induced myoclonus. Drugs in this category include: anti-seizure medications (e.g., valproate, carbamazepine, etc.); antidepressants (e.g., amitryptaline, nortryptaline, desipramine, fluoxetine, sertraline, lithium, etc.); stimulants (e.g., amphetamine, dexedrine, methylphenidate, some asthma inhalers, caffeine, etc.); medications that are toxic to the liver, respiratory depressants, corticosteroids, amiodarone, acyclovir, bismuth, thallium, L-dopa;
  - Myoclonus associated with systemic illness such as dialysis, renal failure, liver failure, pulmonary disease or carbon dioxide intoxication.



PEACE OF MIND

When it comes to your child, you don't compromise. Safety is indispensable. You demand quality. Reliability. Functionality.

The Lisa pediatric postural mobility system from Otto Bock gives you all this while maintaining its playful good looks. So go ahead. Take it "off sidewalk". Recline the back rest up to 130°. Accessorize to your heart's content. And enjoy how easily it folds and how little it weighs. You and your family deserve it.

For more information, visit www.ottobockus.com, or call 1-800-328-4058 to find a dealer near you.

Otto Bock
HEALTH CARE

Circle #63 or visit www.eparent.com/adinfo

continued from page 77

sounds or stimuli, typically involve excessive activity or hyperexcitability of the normal brainstem's "startle circuits." There may also be diminished control in spinal circuits.

HOW IS MYOCLONUS DIAGNOSED AND EVALUATED?

The diagnosis and evaluation of myoclonus may be challenging and is based upon:

(1) a thorough clinical assessment;
(2) evaluation of the nature of the myoclonus with specific testing of muscle activity (electrophysiologic testing);
(3) assessment of where the symptoms occur and factors that provoke or induce episodes of symptoms; and
(4) a comprehensive patient and family history.

The measurement of specific patterns of electrical activity in brain and affected muscle(s) may be necessary to assist the physician in pinpointing specific myoclonic activity. Specialized testing is often conducted, including electrical recording techniques such as:

- **Electromyography (EMG)**: An EMG of the muscles typically shows the duration and frequency of the myoclonic bursts, and whether these bursts spread to other spinal segments (as is seen in propriospinal myoclonus). It may also be helpful in determining whether jerking movements occur simultaneously in more than one limb, or whether they flow gradually down the body.
- **Electroencephalography (EEG)**: During an EEG, small electrodes that are placed on the head measure electrical activity within the brain. Abnormal episodes of activity are recorded and may be evidence for the presence of epilepsy.
- **Reflex studies (evaluation of somatosensory evoked potential (SEP))**: In cortical myoclonus, there may be an excessively large brain electrical response to electrical stimulation of the hands or feet. In some cases, it is also possible to demonstrate the myoclonic electrical signal in muscle. This is done with a "tendon tap," during which the physician literally taps on the tendon of the affected muscle and then observes the electrical response.

In any form of myoclonus, it is important to look for an underlying cause. Any medication or toxin that could produce myoclonic symptoms should be discontinued if possible. The family history needs to be investigated. Metabolic studies may be appropriate, particularly if there are other symptoms or symptoms that are progressively worsening. Metabolic tests may include screening for treatable disorders such as Wilson disease.

Since myoclonus may be a symptom of general systemic illness, including liver failure and some types of tumors, it is important to screen for general health problems. In children with opsoclonus-myoclonus syndrome (myoclonic movements with a random, dance-like jerking of the eyes in all directions), routine tests may include a CT scan or other imaging of the chest and abdomen as well as blood and urine tests. These tests look for evidence of a particular type of nervous system tumor known as a neuroblastoma tumor. A neuroblastoma may cause symptoms that are similar to those found in children with opsoclonus-myoclonus syndrome. These tests help

continued on page 80

Adaptivemall.com™

Shop On-line!

Tim's daughter Carrie.. a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.

Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #23 or visit www.eparent.com/adinfo

THE DUET

The "Go-Anywhere" Wheelchair/Bicycle Tandem

Enjoy the Great Outdoors like never before!

The DUET is a wheelchair bicycle tandem that allows friends and family to go for a ride in comfort and style. The ergonomic seat is relaxing and allows safe supervision in front. Wheelchair separates for use on its own and for transporting. Hub gear system is easy to pedal. Optional electric motor available.

You'll see smiles everywhere you go - everyone wants a ride!

Frank Mobility Systems, Inc.
Toll Free (888) 426-8581 • www.FrankMobility.com

Circle #43 or visit www.eparent.com/adinfo

continued from page 79

to identify a possible neuroblastoma and enable early, appropriate treatment.

An advanced imaging technique known as magnetic resonance imaging (MRI) may be employed to help evaluate for evidence of a tumor, stroke, brain malformation, or other structural lesions near the brain's cortex, the brainstem or the cerebellum. These tests are particularly important if the myoclonus is limited to a particular area of the body or if the child is suspected of having a rare form of epilepsy known as epilepsia partialis continua. Since certain viral infections may cause myoclonus, a spinal tap is sometimes necessary in order to test for such infections.

MYOCLONUS MAY OCCUR ALONG WITH OTHER MOVEMENT DISORDERS

Myoclonus may occur along with other movement disorders. Therefore, physicians should evaluate children for evidence of dystonia, tremor, ataxia, and spasticity. Physicians may also observe for opsoclonus. This eye movement occurs in the opsoclonus-myoclonus-ataxia syndrome, which is characterized by random eye movements, myoclonic movements, and difficulty walking and maintaining balance.

To determine if symptoms improve or worsen with a voluntary activity, physicians may choose to observe children while attempting to drink from a cup. Myoclonic jerks may also be caused by unexpected, loud noises or by a gentle tap on the tip of the nose or on the forehead. Sometimes myoclonic movements have a definite rhythmic pattern and always involve the same area(s) of the body; however, in other children, the symptoms may be without rhythm and move from one part of the body to another.

To test for negative myoclonus, children are asked to extend their arms with the wrists back or to perform some other movement that requires them to hold the limb against gravity. If negative myoclonus is present, the sudden loss of muscle contraction causes the hand or the arm to fall downward.

IS TREATMENT AVAILABLE FOR CHILDREN WITH MYOCLONUS?

Some children with essential myoclonus or essential myoclonus-dystonia improve with small amounts of alcohol. A small amount of alcohol may be administered in order to assist in the diagnosis of myoclonus; however, alcohol is not helpful in long-term treatment.

When a specific cause for myoclonus is identified, such as another movement disorder or other neurologic condition, the symptoms of

THE MELMARK SCHOOL
2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Our approved private day and boarding school serves children ages 5-21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Acquired Brain Injuries
- Cerebral Palsy
- Mental Retardation
- Neurological Disorders

Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

We Offer Your Child:

- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK Ext. 636 or email admissions@melmark.org

Circle #59 or visit www.eparent.com/adinfo

myoclonus are usually effectively resolved by treating the underlying disease. For example, if the identified cause of myoclonus is a tumor within the brain, surgical treatment may resolve the myoclonus.

In certain cases, the treatment of myoclonus is symptomatic and supportive. Symptomatic treatment of myoclonus usually includes the use of benzodiazepines. These belong to a specific class of drugs that act to "slow down" the activities of the central nervous system. These drugs may include clonazepam or diazepam.

OTHER TREATMENTS:

- **Intravenous immunoglobulin** has been used on an experimental basis to treat some children with myoclonus.
- **Plasmapheresis** has been investigated for use in the treatment of certain children with myoclonus. During this procedure, whole blood is removed from the body and then blood plasma (not blood cells) is replaced with saline or a plasma substitute and reinfused into the body. More studies are needed to determine the safety and effectiveness of plasmapheresis for the treatment of myoclonus.

EXAMPLES OF TREATMENT FOR SPECIFIC FORMS OF MYOCLONUS:

- **Immune-mediated myoclonus**, as in children with opsoclonus-myoclonus, typically requires treatment with oral steroids such as prednisone.
- **Juvenile myoclonus epilepsy** usually responds to valproate, and may require life-long treatment.
- **Cortical myoclonus** may respond to valproate, piracetam, or lamotrigine.
- **Myoclonus due to an event involving hypoxia** may respond to 5-hydroxy-tryptophan (5HT). There are scattered reports of this response. It is also possible the 5HT may be helpful for myoclonus that is caused by other factors. EP

For more information visit Kids Move, http://www.kidsmove.org, WE MOVE's new Web site devoted to pediatric movement disorders. Healthcare professionals and parents may access up-to-date information about the recognition, assessment, treatment and avenues of support available for individuals concerned with childhood movement disorders.

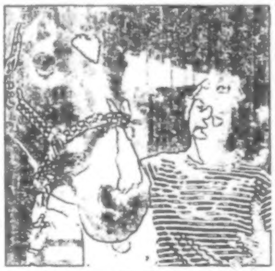
Terence D. Sanger, MD, PhD, is the Director of the Pediatric Movement Disorders Clinic at Lucille Packard Children's Hospital at Stanford University. He is a child neurologist and electrical engineer, and his research laboratory investigates the detailed measurement of movement disorders in children, including ataxia, dystonia, chorea, myoclonus, and spasticity.

Joy E. Bartnett, NASW, AMIA, AMWA, is a medical writer and biomedical informatics specialist for WE MOVE, a not-for-profit organization committed to increasing worldwide education and awareness for movement disorders. For more information, see WE MOVE's Web site: http://www.wemove.org.

A place of *their* own...

A place for encouragement...

A place for friends...



A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #20 or visit www.eparent.com/adinfo

Getting information from EP advertisers is MUCH FASTER ONLINE!

It's as easy as a click of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers

CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in EXCEPTIONAL PARENT.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.

Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
17	ABILITIES EXPO	57
23	ADAPTIVEMALL.COM	79
18	ANDERSON SCHOOL	27
20	ANNANDALE VILLAGE	81
19	ANNE CARLSEN SCHOOL	24
21	ASSISTIVE TECHNOLOGY, INC	47
22	BERKSHIRE MEADOWS	93
24	BODYPOINT DESIGNS, INC	62
27	CAMPHILL SPECIAL SCHOOL	99
29	CHILEDA INSTITUTE	22
30	COLUMBIA MEDICAL	39
31	CONSUMER CARE PRODUCTS, INC	23
32	CONVAID	C2
33	COTTING SCHOOL	91
34	CROTCHED MOUNTAIN REHAB	48
36	CRYSTAL SPRINGS SCHOOL	26
37	CYBERONICS, INC	12-13
	CYCLETOTE CORP	43
38	DURALIFE, INC	54
39	EDEN FOODS, INC	9
200	EP LIBRARY PAGES	94-95
50	EP NEWBORN SCREENING DVD	50-51
199	EP SUBSCRIPTION CARD	17-18
40	EQUIPMENT SHOP	54
41	EVERGREEN CENTER	65
42	FORD MOBILITY	C3
43	FRANK MOBILITY	79
44	FREEDOM MOTORS USA	71
	GENERAL MOTORS	44
45	GLOBAL POWER SYSTEMS INC	61
46	H.D.I.S.	74
47	HARD MANUFACTURING	16
35	HEARTSPRING	45
48	HERTZ SUPPLY CO., INC	55
49	HMS SCHOOL	92
	HOUSE AD	82
51	INNOVATIVE PRODUCTS	53
52	JUDGE ROTENBERG EDUC. CTR.	32
53	KENNEDY KRIEGER	33
54	LAWYERS, INC.	4
55	LITIGATORS, INC.	41
56	MARCH OF DIMES	49
57	MARTHA LLOYD COMMUNITY SERV	26
58	MATHENY SCHOOL & HOSPITAL	74
59	MELMARK	80
60	NAPSEC	92
	NEW ENGLAND VILLAGE	22
61	NEW JERSEY STORM	76
62	OCEAN HYPERBARIC CENTER	31
63	OTTO BOCK	78
64	PRECISION FOODS	37
65	REAL DESIGN	63
66	RED BARN ENTERPRISES	60
67	SIGMA TAU	1-2
68	SNUG SEAT INC	7
69	SOUTH FLORIDA CNTR FOR HOPE	32
70	SOUTHPAW ENTERPRISES, INC	61
71	ST. VINCENT'S SPECIAL NEEDS	35
72	STEWART HOME SCHOOL	99
73	SURE HANDS INTERNATIONAL	56
74	THE BABY JOGGER COMPANY	56
75	THE NYU HOSP FOR JOINT DIS CTR	11
76	TORONTO HYPERBARIC INC	75
77	ULTRAFLEX SYSTEMS, INC.	8
78	VAIL PRODUCTS	C4
79	VERIZON	3
80	VIEWPOINT MOBILITY LLC	53
81	WENZELITE MEDICAL SUPPLY	65
82	WHEELCHAIR GETAWAYS	8
83	WOODBURY PRODUCTS	23
84	WORLD CONGRESS	66-69

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-634-6550

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged.
The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

An Example of Full Inclusion: PREVENTION OF ORAL DISEASES

by Christine Ernst Miller, RDH, MHS, MA

Many of us consider ourselves advocates working to advance full inclusion of individuals with special needs. Significant progress has been made over the past several decades in improving educational, recreational, work-oriented and social opportunities. Yet in the realm of health and total well being, issues related to oral health are one of the most commonly cited problems by people with special needs. Often, just locating a dentist to treat a dental emergency or to repair a tooth is a major accomplishment. Difficulties accessing timely and appropriate dental services combined with complex lives can push prevention of oral diseases off the radar screen for individuals, parents or caregivers. Full inclusion includes prevention of oral diseases.

Prevention of oral diseases is much, much more than a cosmetic task accomplished with a toothbrush. The cornerstone of prevention is really the heart. Being pro-active and caring closely follow and together can overcome most obstacles.

The complete picture of prevention is composed of four major areas: a positive attitude, policy and programs; the adoption of the medical model; assessment; and the use of a customized oral health plan. For a lifetime of oral health without episodes of pain, bleeding or overgrown gums, or loose or decayed teeth, these four areas should be addressed.

Attitude, Policy and Programs

Imagine what life would be like if social service and healthcare professionals, policy makers, legislators and health insurance administrators all considered preventive oral health an essential service for people of all ages with special needs. Results of the 1994-1995 National Health Interview Survey on access to care and use of services by children with special healthcare needs indicated that the most prevalent unmet need was dental care.

Positive attitudes about prevention by the professional team, parents, caregivers, direct support professionals (DSPs) and the person with a disability also have a profound impact on the reality of day-to-day preventive measures. It is time to stop segregating it as a dental-only issue; oral health is an issue of total well-being.

For a lifetime of good oral heath, attitudes and action leading to services should start at infancy. Think of what it would be like if, in early start health programs, infants' and toddlers' oral condition were evaluated along with hearing and vision. Yet even when dental health programs are available they are poorly used. For example, all children and adolescents enrolled in Medicaid are entitled to comprehensive dental services through Early and Periodic Screening, Diagnostic and Treatment program. However, only one in five of those children and adolescents actually receive such services.

Dental professionals and families often cite reimbursement issues as a barrier to care. What if there were a dental insurance coverage for "extra time and management"? Or if imagine adult prevention services were covered by Medicaid nationally, not just in some states? Even with existing insurance coverage, 55 percent of preschool-age children and 50 percent of school-age children do not have private dental insurance. For African-American preschool-age children, 65 percent are without coverage from private dental insurance.

Adoption of the Medical Model

Two types of diseases can occur in the mouth: cavities (also called decay and caries) and gum disease. Cavities and gum disease are the result of different types of bacteria and the body's reaction to them.

Diet, Demineralization and Dental Caries

What causes cavities in children and adults? Cavities are caused by acids which are produced when bacteria eat available sugars in the mouth. Sugar foods are fermentable carbohydrates such as sucrose, glucose, fructose and cooked starch. Cavity-causing (cariogenic) bacteria plus fermentable carbohydrates yield organic acids which can dissolve or demineralize teeth

Many people with special needs can be at greater risk of this dissolving process because of developmental disorders which cause weaker enamel. Additionally, some people have conditions such as GERD (gastro-esophageal reflux disease) that bring up acid from the stomach to the mouth. These acids too can dissolve the teeth.

continued on page 86

Suggestions for preventing oral diseases

Infants and toddlers:

Keep an infant's gums clean by rubbing gently with a washcloth moistened with water. This activity also can be a desensitization technique for children who are tactile defensive

Use a flexible, soft-bristled child toothbrush as teeth erupt.

Ensure daily fluoride by using a very small pea-sized amount of fluoridated toothpaste, starting at the age of one year. Wipe out excess toothpaste.

Seek an oral health consultation within six months of the eruption of the first tooth, as recommended by the American Academy of Pediatric Dentistry. This gives the child a pleasant, low-pressure experience with the health professional and can catch any problems, such as "nursing bottle mouth," early.

Avoid putting the baby to bed with a bottle of sweetened fluid (formula, breast milk or fruit juice). Instead, slowly dilute the liquid with water over several weeks and later use water only. Similarly, avoid leaving a bottle or sipper cup of sweetened fluid with the baby all day.

Infants' parents' and close caregivers' oral condition should be healthy, without active new carious(decay) areas . Mothers should have regular annual dental check-ups before and after the baby is born.

Parents and caregivers should examine their own prevention practices and attitudes about oral care visiting the dentist. What messages are being sent?

Some medications contain more than 50 percent sugar. When possible, have the child rinse and, especially at bedtime, brush the teeth and follow with a fluoride rinse or swab.

Ask about additional sources of topical fluoride to help with tooth repair.

Review the child's snacking behavior and/or food rewards used throughout the day. Day-long snacking on cereal, crackers and sweets feeds the cavity bacteria.

Ages 6 to 12 years

Place sealants on the new permanent molars. Watch for the eruption of the first permanent molars, starting when the child is about the age of six. Sealants are protective plastic coatings on the chewing surfaces of the teeth.

Look for excessive tooth crowding and ask if an orthodontic consultation is needed.

Continue with regular teeth cleanings and exams.

Examine the quality of the toothbrush. Use only a flexible, soft brush. Avoid hard and stiff brushes, as they can hurt and thus contribute to resistant behavior. Store each person's brush separately. Consider whether an electric brush might help now.

Consult with professionals. Use over-the-counter fluoride rinses or swabs once or twice a day for one minute, and brush with a fluoride-containing toothpaste.

Use floss holders to help the individual become as independent as possible and to protect against gum disease.

Use other rewards for behavior besides food. Especially avoid frequent use of decay-producing food such as candy, gum, soft drinks, etc., as rewards for desirable behavior at home and school.

Use mouth guards for children playing contact sports.

Adolescents and Adults

Arrange annual oral exams and annual or semiannual teeth cleanings. If the dental office does a "toothbrush" cleaning which lasts about 10 minutes, then the calculus/tartar will not be removed. Ask about a complete teeth cleaning.

Confirm that an oral cancer exam is done at the annual dental exam. Check regardless of whether or not the individual is using tobacco products—including chewing tobacco. This exam is needed for everyone as they age, including people without any teeth.

Consult with a behaviorist and other professionals, as needed, to maximize independence and acceptance of daily preventive measures.

Save all the teeth you can. When teeth are removed, the bone that supported those teeth slowly disappears (resorbs). Over time this leaves less and less bone for partials and dentures. When people are placed on soft, pureed diets because lack of teeth and/or poor chewing ability, constipation is more likely.

Continue to monitor access to foods and drinks containing sugars (fermentable carbohydrates) such as sucrose, glucose, and fructose. Unlimited access all day long to vending machines filled with these items at school and work is very tempting.

Continue to protect individuals prone to falling against trauma to the face and teeth.

Watch for behavioral signs in non-verbal communicators, such as refusal to eat or drink; head banging or rocking; hands or fingers in the mouth; or a rapid change in temperament such as an increase in social withdrawal. These actions may indicate the person has oral pain or infections

BEST COPY AVAILABLE

If the dissolving process is caught early, then the tooth can be repaired (remineralized) by the saliva. When saliva also has fluoride in it, the tooth repair is stronger. An added benefit is that the fluoride-repaired tooth is even more resistant to future acid attacks. Fluoride can come from drinking water, fluoride-containing toothpaste, and over-the-counter (OTC) products. Fluoridated water reduces by half the number of cavities a child could get. Stronger concentrations of fluoride for home use are available by prescription or can be applied in the dental office.

The Importance of Saliva

Good saliva flow is critical for maintaining strong tooth enamel. Often throughout the day, after we snack, drink or eat, the dissolving (demineralization) and repairing (remineralization) battle takes place in our mouths. The dissolving process is related to the acid-base balance in the mouth. Normally the pH or acid-base measure of saliva is neutral (pH of 7). When sugar foods are eaten and cavity-causing bacteria are present, in the first 5 minutes the pH drops and becomes more acidic (pH of 4). This acid environment makes possible the dissolving-the-teeth process. Over the next 25 minutes, the saliva, if available, neutralizes the acid, and the dissolving process stops.

It takes about 30 minutes after the sugar exposure for the acid-base balance to return to neutral (pH 7). Saliva makes this neutralizing—also called buffering—process possible. Yet people with special needs frequently take medications (including psychotropic drugs and antihypertensives) which dry out the mouth or reduce salivation (xerostomia). Thus, the buffering benefit of the saliva is diminished, and those people are more at risk for cavities.

Prevention of Dental Caries and Gum Disease

Several practical strategies for preventing cavities in high-risk people include: conducting a caries risk assessment of an infant's parents with active decay; use of an anti-bacterial agent, such as chlorhexidine, or fluoride varnish; checking for an adequate amount of saliva; enhancing the saliva remineralization process with a fluoride mouthrinse twice a day; reducing the number of cavity-causing bacteria by brushing and flossing twice a day; and protecting the chewing surfaces of permanent molars with sealants. Further research and consensus development conferences are needed to establish practical clinical protocols for high-risk groups.

Infants are not born with cavity-causing bacteria. When parents or other caregivers share food, for example, spoons, etc., thenthe bacteria can spread. Although the experts may disagree when the "window of infection" occurs, the proposed time period is between 18 months and 2 years old. However, bacteria may be transmitted as early as birth. If parents of infants have active cavity problems, then they should be examined and treated too. Recent research reported that use of xylitol gum by mothers reduced the spread (colonization) of cavity bacteria to infants.

To consider dental caries (decay) as a transmissible bacterial infection is a paradigm shift for many health professionals and the public. Adoption of the medical model in dentistry means focusing on who is most at risk and addressing the cause of cavities—the bacteria—rather than the result—the decayed tooth. Consult oral health professionals to customize the prevention plan for the unique needs and abilities of each person.

Another part of the medical model is the

continued on page 89

Partners in Prevention

You are not alone in your interest and advocacy for oral health for people with special needs. Organizations have lay, health and social service professionals who directly serve and work to increase access to restorative and preventive services for people with special needs. Some of these groups include the Academy of Dentistry for Persons with Disabilities(ADPD), founded 50 years ago and a member organization of Special Care Dentistry, ADPD can be reached at www.foscod.org/adpd.htm and the American Academy of Pediatric Dentistry , with resources on the Links, Links, Links page; reach them at: www.aapd.org. Special Olympics, Special Smiles at www.specialsmiles.org has information and links. For educational resources, the National Oral Health Information Clearinghouse (NOHIC) lists can be accessed at http://www.nohic.nidcr.nih.gov

To locate services or speakers in your area for parents, caregivers, DSPs, etc., start by asking your general dentist or pediatric dentist. Or find your local dental or dental hygiene school by accessing the American Dental Educators Association (ADEA, formerly AADS) at http://www.aads.jvs.edu. Ask dental schools for clinics and such post-graduate programs as General Practice Residency (GPR) or Advanced Education in General Dentistry (AEGD) Programs. Faculty and residents associated with these clinics as well as alumni may be available in your community. Other resources to locate dental professionals could be the local chapters of their professional societies. For example, to identify your local dental society chapter, contact the American Dental Association (ADA) Web site at http://www.ada.org; the Hispanic Dental Association at http://www.hdassoc. org; and/or the National Dental Association at http://www.ndaonline.org. To identify your local dental hygiene society/component, contact the American Dental Hygiene Association (ADHA) at: http://www.adha.org.

BEST COPY AVAILABLE

OVERCOMING OBSTACLES TO DENTAL HEALTH

ORAL HEALTH CARE PLAN

Name ____________________ **Caregiver Name** ____________________ **Date** __________

Assessment

a. Physical problems with oral hygiene: ____________________

b. Behavioral problems with oral hygiene: ____________________

Physical Skills and Aids

a. Skills being learned: ____________________

b. Special aids: ☐ adapted toothbrush ☐ adapted floss holder ☐ electric toothbrush

c. Schedule for using disclosing tablets:

Plan for Partial Participation (☐ not needed-person is independent)

a. Best position for assisting with oral hygiene: ☐ couch, ☐ bean-bag chair, ☐ other:

____

b. Techniques and/or aids used by caregivers: ☐ mouth prop, ☐ floss holder

c. What part does caregiver perform: ____________________

Plan for Structuring the Environment

a. Oral hygiene time and place: ____________________

b. Are infection control procedures being used: ____________________

c. Who will work with the individual: AM ____________________

PM ____________________

Plan for Engaging the Client

a. Choices being offered: ____________________

b. Limits the client can set: ____________________

Plan for Reinforcers

a. What reinforcers are being used currently (e.g. music, book, TV): __________

____

Plan for Shaping

a. What steps are being taught: ____________________

____

b. What level of prompts is currently being used?

☐ Physical (hand-over-hand), ☐ Physical (touch), ☐ Pointing, ☐ Verbal

Other Prevention Actions

a. Fluoride rinses: ☐ Person rinses and empties mouth, ☐ Caregiver uses swab technique

b. Chlorhexidine: ☐ Person rinses and empties mouth, ☐ Caregiver uses swab technique

c. Diet: ☐ Decrease exposure to sugar and starches:

Professional visits and recommendations

a. Last dental cleaning appointment: Date ________ Next appointment date: ________

b. Next dental check up or treatment appointment: ________

University of the Pacific School of Dentistry - Department of Dental Practice and Community Service - 2155 Webster Street, San Francisco, CA 94115 - (415)929-6428 (c)1998

continued from page 87

concept of repairing or remineralizing the tooth. If cavities are caught early, then an over-the-counter (OTC) fluoride mouthrinse used twice daily for one minute could be beneficial. In the past, removing the diseased part of the tooth often was the focus of dental care. Fillings have little long-term effect on the cavity-causing bacteria.

Prevention of Gum Disease

Reducing the number of bacteria is also helpful for the prevention of gum disease. This is accomplished by focusing the toothbrush where the bacteria are most numerous: at the gumline, where the tooth and gums meet. Many bacteria also live between the teeth. Flossing can disrupt those bacteria and can be made easier with a floss holder. Some high-risk people

Make It a Healthy Smile: Finding what works for your child

Contributed by the HMS School

Kristen Millar

Kristen Millar, who has severe disabilities as a result of cerebral palsy, lives with her mother in Warminster, PA and attends Philadelphia's HMS School for Children With Cerebral Palsy as a five-day resident student. Although her parents separated twelve years ago, Kristen's father remains actively involved, spending time with her every weekend. She also has a close relationship with her older sister Jessica, who is married and lives nearby. Totally dependent on her family and life-skills assistants at school for all personal care activities, Kristen uses a manual wheelchair because she can't control a power chair. Although she cannot speak, she manages to communicate many of her needs and reactions with facial expressions and sounds. "She's not a grumpy kid, but she is persistent," said Mrs. Millar.

Kristen is unable to take anything by mouth because of poor muscle control, and receives all nutrition through a gastrostomy tube. She also drools appreciably and might gag or aspirate. Her condition has been further complicated by several bouts of acute pancreatitis and issues with gastric emptying. Despite two recent and difficult hospitalizations, Kristen has been remarkably healthy and retains her cheerful disposition.

Tube feeding has an impact on Kristen's oral health. On a positive note, she has no cavities because, unlike most young people, she doesn't eat refined sugars. But chewing helps to clean the teeth and stimulate the gums. With tube feeding, Kristen misses those benefits. In addition, saliva pools in her mouth, promoting an extreme buildup of calculus (also called plaque or tartar).

Kristen's family and the school work together to provide two critical aspects of her preventive oral care—brushing her teeth several times daily, and scheduling regular professional cleanings to remove the calculus and examine her teeth and gums. Through trial and error, her family and caregivers have learned the most successful approaches.

Mrs. Millar said, "Power toothbrushes have been the latest, greatest invention for her home care. They've made the process more gentle and productive for her." She brushes Kristen's teeth in the shower, with the water turned off. Kristen sits up in a shower chair where her head is elevated, facilitating the brushing. Mrs. Millar said, "It works so well...Kristen loves the shower, and the shower is so easy to clean up." Mrs. Millar taught Kristen to spit out toothpaste by making it a game rather than a chore. Over time, she has also talked a lot about not biting down on the toothbrush. She said, "Kristen's very cooperative for a kid who's extremely sensitive physically, particularly to touch around her mouth, but she does tend to bite down or regurgitate a little." Together, Kristen and her mother have worked out the kinks. Mrs. Millar said, "Earlier, her dental care was harder to do—she cooperates more now. We've become a better team, Kristen and I."

At HMS school, life skills assistant Linda Table is one of the staffers who clean Kristen's teeth three times a day with an electric toothbrush, to more easily remove tartar. Ms. Table uses only a small dab of toothpaste to avoid too much foam, which might cause Kristen to gag. She stands behind Kristen, using one hand to support Kristen's head with her mouth open so that she won't bite down and the other hand to brush. The process takes about five minutes. Linda said, "Kristen has a good attitude about it. She doesn't get upset easily." As part of her preventive care at HMS, consultants Dr. Robert Lloyd or Dr. Manuel Album examine Kristen every three months and clean her teeth with an ultrasonic scaler.

Protecting Kristen's oral health is an essential aspect of her total medical care. Good dental care also protects her lovely smile and visual appeal—an important part of positive social interactions at home, at school, and in the community. Kristen's family strives to give her oral pleasures without compromising her health. They'll apply flavored lip gloss to her mouth or give her a taste of different foods by putting a tiny bit on a finger and touching Kristen's lips. Mrs. Millar said, "She absolutely loves it. She'll stare at you, as if to say 'I want that and I want it now.'" She added, "We're crazy about Kristen. We get recharged hanging out with her."

BEST COPY AVAILABLE

continued from page 89

may also need a brush-on prescription antibiotic. With people who can spit out, use a fluoridated toothpaste, which will also help fight cavities.

Seek professional advice about the status of the gums, follow prevention recommendations and get regular teeth cleanings—once or twice a year. Some people at high risk may benefit from teeth cleanings 3 to 4 times per year, but logistics and cost can be a barrier. If cleanings are done twice a year under general anesthesia, then careful evaluation of the risk to the individual should be reviewed.

Overcoming behavioral, physical and informational barriers

For those individuals with special needs who need assistance or have behavior issues, there are a number of aids to make brushing easier, faster and more fun. Double-sided toothbrushes with flexible soft bristles are now available. With one motion, both sides of the tooth are brushed at the same time. To make the handle larger so the individual can be as independent as possible, poke a hole in a rubber ball 2 or 3 inches across and put the toothbrush handle into the ball. Powered toothbrushes are now available for about $20 to $25 per unit. A person's degree of independence is increased and assistance from the caregiver is lessened when the toothbrush used correctly.

Mouth props can be used to help hold the mouth open. These can be made with tongue blades and a washcloth, or they may be purchased. Assisting a person who needs help for most or all of the cleaning can be accomplished in another room, on the sofa or in other positions that are more comfortable for both of you. You can use a bowl for the person to spit into, or avoid the use of toothpaste. It is the physical movement of the bristles that disturbs the gum-disease bacteria; toothpaste is not needed.

Oral Health Assessments

Oral assessments are one way to put oral health on the radar screen. Physicians, nurses, social workers, OTs, PTs, nutritionists and agency administrators, plus individuals, caregivers or DSPs, should all be promoting oral health assessments. For example, in several social service agencies in California, one nutritionist and a physician were instrumental in starting agency-wide programs for oral health assessment.

Beyond the assessment, it is both professionals and those at home who must make the assessment and the customized preventive recommendations a reality on a day-by-day basis. For example, if the programs directors in a social service agency for people with special needs do not convey that total healthcare includes dental disease prevention, then the team—from the case manager to the parent—is likely to view prevention as a luxury or cosmetic task. It will not matter if a fluoride rinse or an electric toothbrush is in the cabinet if there is no oral health plan nor an expectation that preventive measures are a daily priority. This applies to individuals living with family, independently or in community-care facilities.

The Customized Oral Healthcare Plan

With the complex medical, nutritional, and social issues of children and adults with special needs, it can be challenging to remember oral health. But preventing gum and decay diseases today saves teeth and is easier than correcting the problem later. A plan helps everyone remember to prevent oral diseases. Copies of it should be found in the person's health chart and in binders in group homes, and it should be reviewed annually. The individual and the family should be educated to ask for this so it is written into the individual program plan (IPP) or the individual family service plan (IFSP).

An oral healthcare plan should address the various obstacles to oral health. Commonly cited obstacles can be divided into behavioral, physical, and informational (see the side bar for tips on prevention of gum and decay diseases). In surveys of parents, caregivers and DSPs, behavior issues are frequently listed as the biggest problem in carrying out regular oral healthcare processes. Desensitization, structuring the environment, and a reward system are some of the techniques for overcoming behavioral obstacles.

Addressing physical obstacles, such as a person's inability to hold a toothbrush or need for help with all or some of the hygiene, should be in the plan. Informational barriers can be eliminated through education and follow-up (see box, **Partners in Prevention and Suggestions for Prevention**).

To be comprehensive, the oral care plan must consider the full spectrum of preventive measures available today, such as reduction in sucrose exposure; use of fluoride by mouthrinse or swabbing; fluoride varnishes, sealants; chlorhexidine swabs or rinses; xylitol gum; and regular teeth cleanings.

The Last Word

The difficulties children and adults experience in accessing timely and appropriate dental care highlight the need for regular preventive measures. The increased vulnerability to dental decay and gum disease because of dry mouth, dependency on others, and competing, complex social and health issues, is further indication of the need for aggressive prevention measures. Progressive attitudes about providing preventive care and restorative and emergency dental services are the initial requisites of ensuring a lifetime of oral health.

Prevention-oriented attitudes serve as catalysts to promote the full inclusion of people with special needs into humane and timely preventive oral care. Prevention of oral diseases is much more a matter of the heart than the mind. Together we can make prevention a reality for people of all ages with special needs.

Christine Ernst Miller, RDH, MHS, MA is an Associate Professor, Director of Community Programs and co-Director of the Center for Oral Health for People with Special Needs at the University of the Pacific School of Dentistry. Also, she is President of the Academy of Dentistry for People with Disabilities.

NATIONAL

Ability Camp, Inc.
Center for Conductive Education and Hyperbaric Oxygen Therapy Providing separate and combined programs for children with C.P. For a free video call
1-800-442-6992
www.abilitycamp.com
Circle # 16
See our ad on page 97

CALIFORNIA

The Bridge School
545 Eucalyptus Avenue
Hillsborough, CA 94010
(650) 696-7295 (650) 342-7598
www.bridgeschool.org
The Bridge School serves individuals who use AAC and AT. We operate a K-8 school program as well as many outreach projects including Building Bridges Camp.

CONNECTICUT

St. Vincent's Special Needs Services
95 Merritt Blvd.
Trumbull, CT 06611
(203) 375-6400
Fax: (203) 380-1190
✉ feroleto.child.dev@snet.net
Providing education and therapeutic day programs for children, 0-21 with multiple medical/developmental needs.
Circle # 71
See our ad on page 35

GEORGIA

Annandale Village
3500 Annandale Lane
Suwanee, GA 30024
(770) 945-8381
Fax: (770) 945-8693
www.annandale.org
Full residential and day programs paid vocational training, job placement, recreational activities, case mgt., creative and performing arts, meals and counseling
Circle # 20
See our ad on page 81

KANSAS

Heartspring
8700 East 29th Street N.
Wichita, KS 67226 (800) 835-1043
(800) 835-1043
Fax: (316) 634-0555
Our campus provides a positive, practical environment for multidisciplinary programs that include education, life skills, communication, and behavior management. We serve children ages 5-21 with multiple disabilities.
www.heartspring.org
Circle # 35
See our ad on page 45

KENTUCKY

Stewart Home School
4200 Lawrenceburg Road Dept. B
Frankfort, KY 40601
(502) 227-4821
Fax: (502) 227-3013
www.stewarthome.com
Circle # 77
See our ad on page 99

MASSACHUSETTS

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 02136
(413) 528-2523
Fax: (413) 528-0293
For people of all ages with severe developmental delay. They may be medically involved. We offer comprehensive and integrated medical residential and educational services. All therapeutic services are included.
www.berkshiremeadows.org
Circle # 22
See our ad on page 93

Cotting School
453 Concord Avenue
Lexington, MA 02421
(781) 862-7323
✉ e-mail: jbrownsmith@cotting.org
www.cotting.org &
www.cottinghopehouse.org
A day school for students with physical, learning, medical and communication challenges.
Circle # 33
See our ad on page 91

Evergreen Center
345 Fortune Boulevard
Milford, MA 01757
(508) 478-2631
Fax: (508) 634-3251
www.evergreenctr.org
✉ services@evergreen.org
Circle # 41
See our ad on page 65

IDDI, Crystal Springs School
38 Narrows Road
Assonet, MA 02702
(800) 840-8087 ext. 375
Fax: (508) 644-2008
✉ Css372@aol.com
Circle # 36
See our ad on page 26

Judge Rotenberg Educational Center
240 Turnpike Street
Canton, MA 02021
(781) 828-2202
Fax: (7810 828-2804
✉ k.lachance@judgerc.org
www.judgerc.org
Circle # 52
See our ad on page 32

New England Center for Children
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Fax: (508) 485-3421
www.necc.org
State of the art day/residential school and group homes for children with autism, PDD, developmental disabilities & behavior disorders, age 3-22. Curriculum covers communication, academics, social & life skills, employment. Recipient of U.S. Dept. of Education's National Award for Model Professional Development.

New England Village, Inc.
664 School Street
Pembroke, MA 02359
(781) 293-5461
Fax: 781-294-8385
✉ jandracchio@newenglandvillage.org
www.newenglandvillage.org
See our ad on page 22

Riverbrook Residence, Inc.
4 Ice Glen Road, P.O. Box 478
Stockbridge, MA 01262
(413) 298-4926
Fax: (413) 298-5166
www.riverbrook.org
✉ riverbro@berkshire.net
Serving women with MR Opportunities for voc., social and creative growth. Shared living in integrated community setting 24 hr. supports.

NEW HAMPSHIRE

Crotched Mountain Rehabilitation Center
1 Verney Drive
Greenfield, NH 03047
(603) 547-3311
Fax: (603) 547-3232
Fully accredited by the NEASC and CARF, the Crotched Mountain Rehabilitation Center offers the very best of residential and day programs for children with complex special needs. Visit our Internet site at:
http://www.cmf.org
Circle # 34
See our ad on page 48

NEW JERSEY

Davis Centers Inc.
98 Rt. 46 West
Budd Lake, NJ 07828
973-347-7662
Fax: 973-691-0611
www.thedaviscenter.com
✉ info@thedaviscenter.com
Offering AIT, Tomatis, BioAcoustics, Interactive Metronome, Fast ForWord, Read Spell Comprehend, The Listening Program, OT, hearing, speech and CAP testing

Loneliness shouldn't be a side effect of your child's disability.

At Cotting School, boys and girls of all ages and abilities receive countless opportunities to make friends . . . in the classroom, on a field trip, during basketball practice or in physical therapy. As self-esteem increases with each new friendship, talent and personality shine.

OPENINGS FOR YOUNG PEOPLE FOR 2002 – 2003
NEW POSTGRADUATE RESIDENTIAL PROGRAM NOW OPEN

Cotting School —
where your child belongs.
For information or a tour, please call
Janine Brown-Smith at (781) 862-7323.
www.cotting.org www.cottinghopehouse.org

Cotting
SCHOOL

Cotting School is a 766-approved day school in Lexington, MA for children and youth ages 3-22 with physical, communication, and other challenges to learning.

Circle #33 or visit www.eparent.com/adinfo

National Association of Private
Special Education Centers

NAPSEC is a nonprofit association whose mission is to ensure access for individuals to private special education as a vital component of the continuum of appropriate placements and services in American education.

Free Referral Service
NAPSEC provides information on potential placement options to parents and professionals who need an appropriate private special education and/or therapeutic setting.

National Representation
NAPSEC advocates for the rights of individuals with disabilities and their families.

Nationwide Membership
NAPSEC represents private special education facilities throughout the US by providing a wide array of membership services.

Private early intervention services, schools, residential therapeutic centers, and adult living programs serving individuals with disabilities and their families since 1971

NAPSEC
1522 K Street, NW, Suite 1032
Washington, DC 20005
Phone: 202-408-3338
Fax: 202-408-3340
E-mail: napsec@aol.com
Web Site: www.napsec.com

NAPSEC

Circle #60 or visit www.eparent.com/adinfo

Personalized Interdisciplinary Programs

HMS School for Children with Cerebral Palsy serves children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- **Physical & Occupational Therapies**
- **Special Education**
- **Speech/Language Therapy**
- **Music Therapy**
- **Communication Aids**
- **Special Medical Attention**
- **Adapted Recreational Activities**

Computer Technology
Communication Devices
Environmental Control
Powered Mobility

HMS, founded in 1882, is open to students two to 21 years. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy

4400 Baltimore Ave, Philadelphia, PA 19104
(215)222-2566

Circle #49 or visit www.eparent.com/adinfo

MATHENY SCHOOL AND HOSPITAL
P.O. Box 339, Main Street
Peapack, NJ 07977
(908) 234-0011
✉ info@matheny.org
www.matheny.org
Res., outpt., ed (3-21), respite for d.d.
Circle # 58
See our ad on page 74

NEW YORK

ANDERSON SCHOOL
4885 Route 9
Staatsburg, NY 12580
845-889-4034
Fax: 845-889-3104
www.andersonschool.org
Residential/Day school serving children ages 5-21 who have been diagnosed with autism or other developmental disabilities dedicated to providing the highest quality programs possible.
Circle # 18
See our ad on page 27

PATHFINDER VILLAGE FOR DOWN SYNDROME
3 Chenango Road
Edmeston, NY 13335
(607) 965-8377
www.pathfindervillage.org
✉ info@pathfindervillage.org

NORTH DAKOTA

ANNE CARLSEN CENTER FOR CHILDREN
301 7th Avenue NW
Jamestown, ND 58401
(800) 568-5175
Phone/Fax (701) 252-3850
www.annecenter.org
Educational, therapeutic and residential services through age 21. Our evaluation team travels to your home and school setting.
Circle # 19
See our ad on page 24

OREGON

CAMP ATTITUDE!
A natural place for children with disabilities and their families. Located near Sweet Home, Oregon. 1 or 2 wk sessions during summer.
Campattitude.com
541-924-1400
Fax 541-924-0379
All ages & disabilities welcome!

UPWARD BOUND CAMP FOR PERSONS WITH SPECIAL NEEDS
P.O. Box C
Stayton, OR 97383
(503) 897-244
Fax: (503) 897-4116
ACA accredited Christian program serving persons 12 yrs-80+ yrs w/primary label of MR/DD skilled staff, fun & friends year round camp & respite.

PENNSYLVANIA

CAMPHILL SPECIAL SCHOOL
1784 Fairview Road
Glenmoore, PA 19343
(610) 469-9236
Fax: (610) 469-9758
www.beaverrun.org
✉ bvrrn@aol.com
Circle # 27
See our ad on page 99

DEVEREUX
444 Devereux Drive
P.O. Box 638
Villanova, PA 19085
Toll Free (800) 345-1292
(610) 520-3000
FAX: (610)542-3100
Devereux-A nationwide network of residential and day treatment programs for children and adults who have a wide range of emotional and or developmental disabilities.

DR. GERTRUDE A. BARBER CENTER
136 East Avenue
Erie, PA 16507
(814) 453-7661
Fax: (814) 454-2771
✉ gabcmain@drbarbercenter.org
Educational/residential/vocational/employment facility serving children and adults with disabilities with state of the art programming.

ELWYN
111 Elwyn Road
Elwyn, PA 19063
610.891.2196
Fax: 610.891.2903
www.elwyn.org
150 years of educating children with special needs; day & residential options from birth to 21; early intervention, integrated preschool, elem. & secondary Ed; therapeutic summer day camp for children with autism and Asperger Syndrome.

HMS SCHOOL FOR CHILDREN WITH CEREBRAL PALSY
4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566
Fax: (215) 222-1889
Circle # 49
See our ad on page 92

LIFEPATH/RIDGE CREST
22 Almont Road
Sellersville, PA 18960
(215) 257-0471, ext. 150
Fax: (215) 257-7928
www.ridge-crest.org
Summer camp: long-term & short term residential care for medically fragile children * respite care * available upon request.

MARTHA LLOYD COMMUNITY SERVICES
190 West Main St.
Troy, PA 16947
570-297-2185
Fax: 570-297-1019
✉ information@marthlloyd.org
www.marthalloyd.org
Circle # 57
See our ad on page 26

MELMARK, INC.
2600 Wayland Road
Berwyn, PA 19312
1-888-MELMARK
Fax: (610) 353-4956
www.melmark.org
Approved private school with 24-hour learning model, adult day programs, & residential alternatives for children & adults with dev. disabilities. 24- hour nursing care, OT/PT; adaptive therapies; aquatics, hippotherapy, recreation, & multi-sensory programs.
Circle # 59
See our ad on page 80

SOUTH DAKOTA

CHILDREN'S CARE HOSPITAL & SCHOOL
2501 W. 26th Street
Sioux Falls, SD 57105-2498
(605) 782-2300 or (800) 584-9294
Private, nonprofit facility with outreach, outpatient, day & summer school and residential services for children with disabilities. Pediatric & adult outpatient services now offered at the CCHS Rehabilitation Center, 1100 W. 41st Street. Accredited rehabilitation programs.
http://www.cchs.org
Circle # 28
See our ad on page 97

TEXAS

AVONDALE HOUSE
3611 Cummins
Houston, TX 77027
(713) 993-9544
Fax: (713) 993-0751
www.avondalehouse.org
Provides school, residential, and day habilitation services to children and young adults with autism.

MARBRIDGE SUMMER CAMP
P.O. Box 2250
Manchaca, TX 78652
(512) 282-1144
www.marbridge.org
Located just south of Austin, Camp Marbridge provides opportunities for young adults with special needs to meet new friends, have fun, and make strides in social development and independent living skills.

TEXAS NEUROREHAB CENTER
1106 West Dittmar Road
Austin, TX 78745
(800) 252-5151 or (512) 444-4835
Fax: (512) 462-6636
Providing brain injury/ neurobehavioral treatment for children & adolescents with complex medical, physical and/or behavioral issues.

WASHINGTON, DC

THE NATIONAL ASSOCIATION OF PRIVATE
Schools for Exceptional Children (NAPSEC)
1522 K Street, NW
Suite 1032
Washington, DC 20005
202-408-3338
Fax: 202-408-3340
✉ napsec@aol.com
www.napsec.com
Circle # 60
See our ad on page 92

WISCONSIN

BETHESDA LUTHERAN HOMES & SERVICES, INC.
700 Hoffmann Dr
Watertown, WI 53094
(800) 369-4636
Fax: (920) 262-6513
http://www.blhs.org

CHILEDA INSTITUTE
1020 Mississippi Street
LaCrosse, WI 54601
(608) 782-6480
Fax: (608) 782-6481
www.chileda.org
Circle # 29
See our ad on page 22

Berkshire Meadows

Nestled in the serene beauty of Western Massachusetts' Berkshire Hills, Berkshire Meadows offers a comprehensive, integrated year-round residential program for children, adolescents and young adults who are severely developmentally delayed and may be multiply disabled.

We help our population become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement, and support. We believe that all people, no matter how severe their disabilities, should be given the opportunity to achieve their maximum potential.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523, Ext. 14
berkshiremeadows.org

Circle #22 or visit www.eparent.com/adinfo

WWW.EPLIBRARY.COM

EP Exceptional Parent LIBRARY

THE SPECIAL NEEDS BOOKSTORE

FOR YOUNG PEOPLE

How Many Days Until Tomorrow?
J. Caroline Janover
Josh, a 12-year old with dyslexia, is spending the summer with his older brother and grandparents on a remote Maine island. This is the story of how he finds adventure and discovers new talents in the sometimes rugged wilderness of Maine.
WB7224FY **$11.95**

Mama and Daddy Bear's Divorce
Cornelia Maude Apelman ACSW, LCSW
To a young child, divorce need be explained only in the simplest terms. This book emphasizes the precious things in a child's life that stay the same. The message conveyed is that no matter where the parents live, they will always love their child.
AW121GN **$14.95**

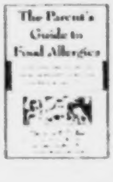
Nursery Rhymes from Mother Goose
Told in Signed English
Harry Bornstein and Karen L. Saulnier; Illustrated by Patricia Peters and Linda Tom
More than a dozen favorite rhymes illustrated with full color paintings accompanied by 380 drawings showing verses in Signed English. Designed to help young readers strengthen their language skills.
GU108YP **$14.95**

PHYSICAL DISABILITY

Torticollis
Differential Diagnosis, Assessment and Treatment, Surgical Management and Bracing
Karen Karmel-Ross, PT, PCS, LMT
Clearly reflects the philosophy of the team approach by including contributions from a pediatric orthopedist, pediatric general surgeons and several pediatric physical therapists. Reviews the differential diagnosis and surgical management of CMT and provides a detailed, comprehensive approach to the nonoperative management of CMT by bringing together a wide range of related materials under one cover.
HP3171DS **$24.95**

Easy for You to Say
Miriam Kaufman, MD
Q & As for Teens Living With Chronic Illness or Disability
This book addresses issues faced by teens and young adults with disabilities and chronic conditions. The information is presented in a straightforward questions and answer format that can easily be browsed through, rather than read cover to cover. Divided into eight chapters to enable the reader to jump to a topic of interest such as Doctors and Medical Issues, Friends and Dating or Sexuality plus much more.
KP6194CI **$15.95**

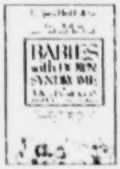
GENERAL



The Parent's Guide to Food Allergies
Clear and Complete Advice From the Experts On Raising Your Food-Allergic Child
Marianne S. Barber with Maryanne Bartoszek Scott M.D. and Elinor Greenberg, Ph.D.
Whether you are the parent, relative, caregiver, or teacher of a food allergic child, you know how challenging it is to keep that child safe, healthy, happy, and well fed. The team of authors behind this invaluable book—the mother of a food allergic child, a board-certified allergist, and a psychologist—will take you through every step of life with a food allergic child. Included issues are: allergy testing what you need to know; diagnosing and treating anaphylaxis; in-depth discussion of top eight most common food allergies; recipes that are easy, delicious and kid friendly plus much more.
HH6004FA **$15.00**

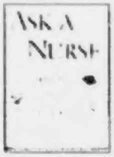
DOWN SYNDROME

Gross Motor Skills in Children with Down Syndrome
A Guide for Parents and Professionals
Patricia C. Winders, PT.
A how-to guide for meeting the challenges Down syndrome presents for gross motor development, coordination of large muscle groups and the sequencing of movements in young children. This book provides guidance for parents of children ages birth through 6 years.
WB171DS **$16.95**



Babies with Down Syndrome
A New Parents' Guide
Second Edition
Edited by K. Stray-Gundersen
A newly revised complete and compassionate guide, written by doctors, nurses, educators, lawyers, and parents.
WB156DS-english **$15.95**
WB178DS-spanish **$15.95**

HEALTHCARE



As A Nurse
From Home Remedies to Hospital Care
Edited by: Geraldine Bednash, Ph.D., R.N., FAAN
This book provides comprehensive information on standard treatments, home remedies, and effective over-the-counter medications for health problems ranging from allergies to yeast infections. With the expertise of 550 nursing schools and personal advice from 100 registered nurses nationwide, you can learn what to do whey your or a family member is sick and in need of care. Chapters are arranged alphabetically so it is easy to find what you need.
SS6875GN **$30.00**

Transcultural Aspects of Perinatal Health Care
A Resource Guide
National Perinatal Association
Offers resources and information supporting requirements of the Office of Civil Rights, the Maternal and Child Health Bureau of HRSA, and JCAHO in Cultural Sensitivity, Cultural Competency, Core Health Status Indicators, Developmental Health Status Indicators, Interpreter Competency and patient education. A great source for Title V Applications. User friendly binder chapters include narrative and support sections; accompanied with a CD-ROM to facilitate searching and referencing. Periodic updates will be available in choice of E-Mail, CD-ROM or printed copy.
EP8020PN **$69.00**

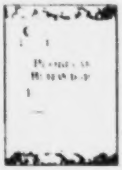
GRIEVING

Remembering With Love
Messages of Hope for the First Year of Grieving and Beyond
Elizabeth Levang, PhD. and Sherokee Ilse
An affirming gift for those grieving the loss of a loved one, offering compassion, comfort and guidance with over three hundred short pieces written by those who have been through the grieving process.
FP040DE **$11.95**

What on Earth Do You Do When Someone Dies
Trevor Romain
A down to earth explanation for children about death. It offers many ways for children to cope with and understand what happens when someone dies.
FS400DE **$7.95**

Guiding Your Child Through Grief
Mary Ann Emswiler, MA, MRS, and James P. Emswiler, MA, M.Ed
This caring and compassionate guide offers expert advice during the difficult days to help a child grieve the death of a parent or sibling. This book helps readers understand the many secret ways children grieve and offers more insightful information, and advice that can help a child heal.
BD0257GR **$13.95**

COMMUNICATION



Communication Based Intervention for Problem Behavior
A User's Guide for Producing Positive Change
Edward G. Carr; Len Levin; Gene McConnachie; Jane I Carlson; Duane C. Kemp and Christopher E. Smith
Consolidating years of important research and personal skill, this step by step guide details innovative methods for managing episodes of problem behavior, conducting initial ongoing functional assessments, selecting and teaching forms of communication, and working toward maintenance and generalization. This is an indispensable resource to help individuals with disabilities curtail problem behavior and gain greater independence in the community.
PB1596GN **$29.95**

Your Child's Speech and Language
Guidelines for Parents **NEW!**
Mary Brooks, Deedra Engmann-Hartung
This charmingly illustrated 52-page book provides information for parents and others who want to know what to expect in the way of speech and language development from infancy through 5 years, and what parents and others can do to help develop normal speech and language.
PB132CM **$14.00**

EP LIBRARY • (800) 535-1910 • EPLIBRARY@AOL.COM

SYNERGISTIC STUTTERING THERAPY

Synergistic Stuttering Therapy
A Holistic Approach
Sr. Charleen Bloom and Donna K. Cooperman, Ph.D.
Learn the details of a program that integrates the principles of speech production with the socioemotional aspects of communication. Discover how to structure individual treatment plans based on attitude, behavior, and interaction within their environment.
BH110CM **$40.00**

INCLUSION

Quick Guides to Inclusion
Ideas for Educating Students with Disabilities
Michael F. Giangreco
With brief factual summaries and to the point suggestions, the book is easy to use and focused on the topics most essential to successful inclusion. An entry level guidebook for new teachers and a concise summary of practices for seasoned professionals.
PB143ED **$22.95**

The Illusion of Full Inclusion
A Comprehensive Critique of a Current Special
James M. Kauffman and Daniel P. Hallahan
A collection of analyses by nationally recognized individuals who raise serious questions about the full inclusion of all students with disabilities into general education.
PE178IN **$31.00**

action for inclusion

Action For Inclusion
How to Improve Schools By Welcoming Children with Special Needs Into Regular Classrooms
O'Brien and Forest with Snow, Pearpoint, and Hasbury
An extraordinary plain language guide to inclusion. Provides a clear presentation of the values behind full inclusion and outlines a sensible series of actions that can be followed to make full inclusion a reality.
IP700ED **$15.00**

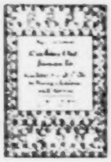
AUTISM

Son Rise
The Miracle Continues
Barry Neil Kaufman
An inspiring journal of a family's successful effort to reach their autistic child. Includes stories of other families who have used the same approach to heal their special children.
OH889AM **$20.00**

Through The Eyes Of Aliens
A Book About Autistic People
Jasmine Lee O'Neil
This is a rich and positive description of how it feels to be autistic and how friends, family and the professionals that work with autistic people can be more sensitive to their needs. Written with a creative spin by an author who is autistic herself.
TF009AT **$24.95**

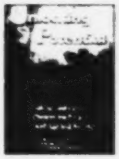
Autism Through the Lifespan
The Eden Model
David L. Holmes, Ed.D.
A unique and detailed look at a successful approach to treating and caring for children with autism. Parents, teachers, and treatment professionals will find this book to be informative and insightful reading.
WB176AT **$21.95**

Exiting Nirvana
A Daughter's Life with Autism
Clara Claiborne Park
The sequel to "The Siege", this book finds Jessy Park, now an adult, still struggling with language, with hypersensitivity's and obsessions, and with the social interactions that ordinary people take for granted but she cannot understand. With the help of family, teachers, and friends, Jessy has achieved more than her parents could have hoped for. This is a moving story about the making of a self and what it means to be human and a contributing active member of her family and community.
LB1176AT **$23.95**



Reaching Out, Joining In
Teaching Social Skills to Young Children with Autism
Mary Jane Weiss, Ph.D., BCBA & Sandra L. Harris Ph.D.
Designed to show parents and professionals how to help young children with Autism with one of their most challenging areas of development—Social behavior this book covers four broad topics. This book focuses on the following areas: play skills; the language of social skills; understanding another person's perspective; and using these skills in an inclusive classroom. This guide offers invaluable expertise and easy to understand activities parents and teachers can practice at home or at school to help kids with autism in preschool through elementary schools become more socially adept.
WB7240AT **$16.95**

ATTENTION DEFICIT



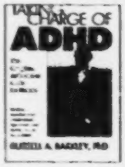
Unlocking Potential
College and Other Choices for People with LD and AD/HD
Juliana M. Taymans, PhD, Lynda L. West, PhD, and Madeline Sullivan, M.A.
This book is an indispensible tool for high school students with learning disabilities who are preparing for life after graduation. Filled with the latest information, advice, as well as practical tips and resources, this book is designed to make the transition from high school a success.
WB9946AD **$18.95**

Distant Drums, Different Drummers

Distant Drums, Different Drummers
A guide for young people with ADHD
Barbara D. Ingersoll, Ph. D.
A view that offers children and adolescents struggling with ADHD the opportunity to see themselves in a positive light due to their penchant for novelty and exploration and boundless energy.
CP100AD **$15.95**

Beyond Ritalin

Beyond Ritalin
Stephen W. Garber, Ph.D., Marianne Daniels Garber, Ph.D., Robyn Freedman Spizman
Facts about medication and other strategies for helping children, adolescents, and adults with ADHD.
HC100AD **$13.50**



Taking Charge of ADHD
The Complete, Authoritative Guide for Parents
Russell A. Barkley, Ph.D.
Pioneering research providing new insight into preventing ADHD from becoming a major obstacle in a child's and parent's life. Step-by-step ways to manage a child in everyday situations. Latest information on medications enhancing school performance and more.
GL030AD **$17.95**

SPINA BIFIDA

An Introduction to Spina Bifida

An Introduction To Spina Bifida
David G. McLone, M.D., Ph.D. and Joy Ito, R.N.
The purpose of this book is to aid the parents, family and non-medical people who care for the child born with spina bifida. Revised 1998
SB095SB **$6.00**

Answering Your Questions About Spina Bifida
A Guide from the Spina Bifida Program Department of General Pediatrics
Edited by C. Shaer
Contains information to help understand basic medical, educational, and social issues of children and adults with spina bifida.
CN152SB-english **$6.95**
CN153SB-spanish **$6.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: EP, Dept. EP0302, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call 800•535•1910

QTY.	ITEM#	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

These prices are subject to change without notice.

Sub-Total
NJ Residents 6% Sales Tax
Shipping
TOTAL

Name ____________________
Address ____________________
City ____________________ State __________ Zip __________
Telephone ____________________ E-Mail ____________________
I have enclosed my check payable to Exceptional Parent or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover
Account Number: ____________________ Exp. Date _____ / _____
Signature ____________________

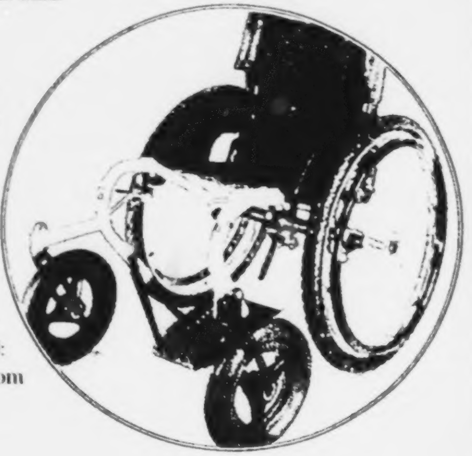
Circle #200

new products

EASIEEATERS CURVED UTENSILS

EasieEaters Curved Utensils are lightweight, easy-to-grip plastic utensils. Designed with thick handles, these utensils are angled to assist with hand to mouth feeding. Sold as a spoon and fork set, they are available for left- or right-handed users and are dishwasher safe. Available in red, blue and purple.

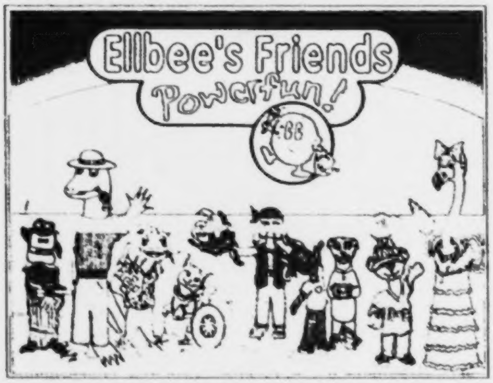
Sammons Preston, An Ability One Company, P.O. Box 5071, Bolingbrook, IL 60440-5071; Phone: (800) 323-5547; Fax: (800) 547-4333; E-mail: sp@sammonspreston.com; Web site: http://www.sammonspreston.com



TERRATREK

The TerraTrek is a lightweight wheelchair made with a high strength chromoly steel frame for maximum durability. The all-terrain wheels with push rims and large front casters make travel at the beach, park or sports fields easier. The TerraTrek also provides wheel locks, adjustable foot rests and a clothing guard. It is available in red, black, yellow, blue and hunter green.

MedBloc, 700 Ensminger Road, Ste. 112, Tonawanda, NY 14150; Phone: (888) 433-6818, (716) 447-0050; Fax: (888) 433-6834, (716) 774-0030; E-mail: info@medbloc.com; Web site: http://www.medbloc.com



ELLBEE'S FRIENDS POWERFUN!

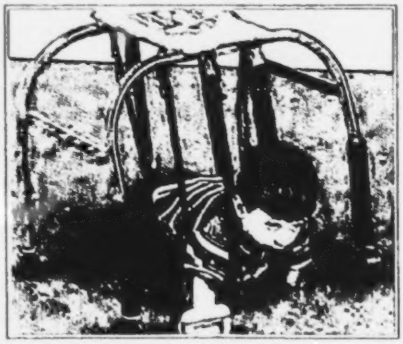
Ellbee's Friends Powerfun is a math tutorial CD series designed to reach out to children ages 6 and up. The addition and multiplication CD features Ellbee the Lint Ball and it's twelve culturally and geographically representative animal friends. These characters come from around the world, and one uses a wheelchair. The series teaches, reinforces and tests math, listening and practicing skills in a fun and self-correcting way which encourages student response. Ellbee's Friends Powerfun can also be used as a springboard into studying other topics such as geography, wildlife, world music and cultures.

Ellbee's Friends Powerfun!, P.O. Box 30111, Chicago, IL 60630; Toll free Phone: (866) 456-9870; Local: (773) 304-0020; E-mail: info@ellbeesmath.com; Web site: http://www.ellbeesmath.com

CREEPSTER CRAWLER

The Creepster Crawler is a crawling aid that promotes movement while providing support for children with physical disabilities during independent locomotion development. The sturdy lightweight frame on pivoting casters includes a padded platform that can support a parent or therapist while working with the child on weight bearing or shifting, reaching and creeping skills. The foam-padded suspended harness system provides adjustable front shoulder and chest straps for an individual fit.

Kaplan Companies, P.O. Box 609, Lewisville, NC 27023-0609; Phone: (800) 334-2014; E-mail: kaplan@kaplanco.com; Web site: http://www.kaplanco.com



The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

PRODUCT SHOWCASE

Product Showcase is a special service for Exceptional Parent readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

Now he has a place for everything like everyone else.

It's unique ball-joint movements and sturdy support put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, and pencils. And when it's time for transfers, the entire desktop swings down to the side.

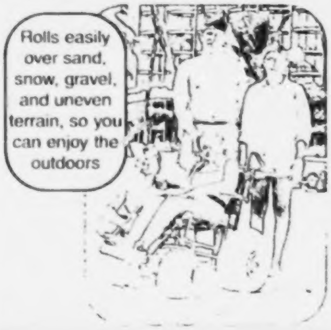
1-800-4 MYDESC

www.mydesc.com
Santa Clara, CA 95056

Circle #1

Natural Access

Expand your horizons with the Landeez All-Terrain Wheelchair!


Rolls easily over sand, snow, gravel, and uneven terrain, so you can enjoy the outdoors

For more info 800-411-7789 or visit
www.landeez.com

Circle #2

freedom

what is your definition?

call us today

1.800.661.9915
www.freedomconcepts.com

Circle #3

LEE MAR SUMMER CAMP

For Children & Teens with Special Needs.

49th year of camp leadership in beautiful Pocono Mountains of PA. Balances program geared to individual needs of campers. All Camp activities plus academics,speech,and language therapy, computers, & life skills training. Highly qualified staff. ACA Accredited. Heated pool. All buildings air conditioned.

LEE MAR SUMMER CAMP

FOR A FREE BROCHURE CONTACT:

Tel: 800-LEE-MAR
Fax: 215-658-1710
Web: www.leemar.com

Mr. Ariel J. Segal, MSW, LSW, Exec. Dir.
805 Redgate Road, Dresher, PA 19025
E-mail: gtour400@aol.com

Circle #26 or visit www.eparent.com/adinfo

A SPECIAL SUMMER

for Children With Hidden Abilities

- Co-ed, residential, 7, 4, 3 week sessions
- Traditional, Adaptive/Therapeutic Recreational Programs for LD, ADD, ADHD, DD, PDD
- Located in beautiful High Falls, New York

Contact: Bruria K. Falik Ph.D.
Camp Huntington
P.O. Box 368
Woodstock, New York 12498
(845) 679-4903
Email: **camphtgtn@aol.com**
www.camphuntington.com

Camp Huntington

ACA Accredited – 41 years

Circle #25 or visit www.eparent.com/adinfo

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

CHILDREN'S CARE HOSPITAL & SCHOOL
For Children with Disabilities and Their Families

CHILDREN'S CARE HOSPITAL & SCHOOL *(formerly Crippled Children's Hospital & School)* is a private, nonprofit facility serving over 1700 children and families each year. Individualized, family-centered programs available through day and summer school, outpatient, outreach, or residence. Accredited pediatric rehabilitation program now offered.

Contact:
Aaron Wimmer, Admissions Liaison
Children's Care Hospital & School
2501 West 26th Street • Sioux Falls, SD 57105-2498
(605) 782-2300 or (800) 584-9294, Ext. 2379

Circle #28 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

MARKETPLACE

ATTORNEY

Attorney Richard Gottesman
(800)295-1107
gottesman@law.com
Cerebral Palsy, Brachial Plexus/Erb's Palsy and Childbirth Injuries

CYCLES

Cycles for Virtually Every Special Need & Age

Amputations, Cerebral Palsy, Spina Bifida, Visual Impairments/ Blindness, and many others

You Can Even Earn Your Own Cycle!
[illegible]-894-5700 FAX: 806-894-1238

Check us out on the Web...
http://www.rocknrollcycles.com

EQUIPMENT DEALERS

American Discount Medical

Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

Special-Needs Collection

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg, PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

HANDWRITING WORKBOOK

Handwriting Made Easy
6933 Tonia Court
Evansville, IN 47710
www.HandwritingMadeEasy.com
PreK/Kindergarten workbook teaches letters/numbers with arrows and colored dots!
Mail $8.00 for each workbook.

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider. Resource information: www.medmarket.com
e-mail: info@archhp

Ask about our Youth Brief sample pack. Only $5.99!

HDIS

FREE CATALOG

Call Today!
1-800-2MY-HOME™
(1-800-269-4663)

MONITORING SYSTEM

Care Electronics Inc.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price. Call for FREE CATALOG

TOYS & HOBBIES

TFH (USA) LTD
4537 6B Sonia RD.
Gibsonia, PA 15044
(800) 467-6222
www.tfhusa.com
e-mail: info@tfhusa.com
Fun products for retreat on and education of special needs children. Request a free catalog.

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/ handling). To order, call 1-800-535-1910.

RESOURCES

JACKIE--
The HeartWarming, Inspirational, True Story of a Remarkable Down Syndrome Girl ...Plus... Parables for Parents of Down Syndrome Children

As told by Jackie's Father, A Licensed Mental Health Professional
DAN JUNOT, LPC, CCHT

A must read for all family members, friends, clergy, family doctors, pediatricians, caseworkers, special education teachers, and other professionals associated with newborn and young mentally retarded children!

You'll love reading *JACKIE!* 110 entertaining pages of laugh-out-loud, cry-out-loud stories...with a point: practical, experience-based advice for nurturing the full potential of special children. You'll revisit *JACKIE* again and again as your child grows. Includes 4 pages of color photographs, that depict and accompany her real life adventures.

Order by Internet, Phone or Mail:
www.centerforspecialservices.com
1-800-510-5235 (24 Hours)
CSS, INC • PO BOX 804
THIBODAUX, LA 70301

$23.00
+$4.00
S&H

ASK FOR ITEM# 715EP

SWITCHES

BUBBLES™ SWITCHES — for those who have difficulty using ordinary switches. Touch-sensitive, or it can be set so the hand only needs to pass near the switch! Convenient dome shape.

MINIMAL MOTION™ SPLINT SWITCH KITS — touch-sensitive switch pads to mount directly on hand splints.

EQUAL ACCESS COMPUTER TECHNOLOGY, INC. 978-466-9191
222 Grant Way, Lancaster, MA 01523
Email: eact@world.std.com

VAN CONVERSION DEALERS

MASSACHUSETTS

Motion Automotive Specialty
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—Day, Week or Month.

To Advertise in Marketplace Contact: Barbara Nastro
Tel: (908) 534-6366 • **Fax:** (908) 534-6941

SHAKE-A-LEG MIAMI

continued from page 58

City of Miami Parks and Recreation Department and serves the public seven days a week. One new program provides sail training to Dade County Public School students as part of their adaptive physical education.

Pre-sail instruction with members of the Youth Program.

Shake-A-Leg also partners with the YMCA, Boys and Girls Clubs, and scouting organizations and even runs a summer water-sports camp. They also work in conjunction with Miami Lighthouse for the Blind and several community-based organizations for people with developmental disabilities. Sailing really is for everyone at Shake-A-Leg!

TOURISTS ARE WELCOME

Such a fabulous resource deserves to be known far and wide. Visitors to South Florida with disabilities and their friends and families should take advantage of this all-too-unique opportunity. Either stop by on Sunday afternoon during Open House, when you can try sailing or sea kayaking for free, or call ahead to reserve a boat and skipper on other days. The rates are very reasonable for all their water sports programs. And what a fabulous setting! Biscayne Bay is always gorgeous, with the city skyline in the background; I've even seen dolphins at play. A wheelchair accessible restaurant, Monty's Seafood House, is right across the parking lot from Shake-A-Leg, perfect for an aftersail drink or dinner. And CocoWalk is just a short drive away. To learn more, contact Allen Fiske, outreach director, Shake-A-Leg Miami. ▪

Laurel Van Horn is the Editor of Open World magazine.

Reprinted from OPEN WORLD, Vol. 4 Issue 2, (Summer 2001). Copyright 2001. All rights reserved.

Resources

Access Dinghies: www.accessdinghy.org

Shake-A-Leg Miami: 2600 South Bayshore Drive, Miami, FL 33133; (305) 858-5550, (Fax) 858-62626; www.shakealegmiami.org

U.S. Sailing Association: www.ussailing.org. Links to more than 50 adaptive sailing programs.

Greater Miami CVB: (800) 240-4282 www.miamiandbeaches.com

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #72 or visit www.eparent.com/adinfo

Camphill Special School
Children's Village

A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- **Pennsylvania Approved Private School**
- **Waldorf Curriculum (Member of AWSNA)**
- **Both Day & Residential Programs Available**

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236
www.BeaverRun.org

Circle #27 or visit www.eparent.com/adinfo

"The ONLY Difference"

by Christa Forman

As a child, Laura loved to open and close the bathroom door. She would stand in the hallway, fully clothed in her torn stocking pajamas, engaging herself in this fun-filled activity. Although she was barely tall enough to reach the doorknob, she continued to push and pull the door. While I sat in a chair across the room, I could see the gigantic smile on her face as her feet scraped and swished against the tile floor. Because she was diagnosed at an early age with pervasive developmental delay, Laura did many things that no one ever understood. Despite all of her limitations and differences, Laura has always been a truly unique and interesting person.

While a person may realize her disability in conversation, Laura's physical appearance does not reveal her differences. She has dark blond hair and deep, sky blue eyes. While many people cut off their hair when it becomes too long, she prefers to keep it long and flowing. She loves the hair to flap in her face. As a child, Laura was skin and bones, a small skeleton with crooked teeth. She would only eat salad. While I devoured everything from strawberries to hotdogs, my sister would eat only lettuce, tomatoes, and French dressing! Today, Laura has a strong passion for all kinds of food.

Laura Forman (left) celebrates Christmas with her sister, Christa, 17, and her brother Willie, 12.

Laura becomes obsessed with things very easily. If she loves something, then she absolutely loves it! When she was 6, she fell in love with *The Wizard of Oz* even though she already collected every figurine known to man, she still needed the movie and the soundtrack. She talked about *The Wizard of Oz* quite often. The following year, Laura grew out of this interest and began her passion for *Oliver!* the movie musical. "Here we go again!" I thought. She raved continuously about Oliver, Dodger, Bill Sykes, and other characters in the film. The lyrics from the musical blared through the house every hour. Still, there were other muses to be had. At the age of 15, her infatuation with the Backstreet Boys started. Covering her doors were posters of these dreamy singing sensations. She had to own any and every magazine which contained the smallest picture of the boys. Today, Laura still remains a true "fanatic" of these boys.

Laura is also a very sweet and caring person. For example, when she was 5 years old, she fell and hit her head on my grandmother's porcelain coffee table. As my brother Willie and I returned from the store, we saw her sitting on the patio with her mouth bleeding. She was immediately rushed to the hospital where her jaw was sewed back to its former shape with countless stitches. When the nurse gave Laura the hospital bracelet, she immediately said (with her mouth full of stitches), "One for Christa and Willie too!" This story reminds me how she constantly thinks of other people.

The other day I watched Laura return to her residential school. I remembered the girl who ate only salad, who loved to open and close the bathroom door, and who thought about me even in times of pain. As I watched her enter her house, I realized that Laura has never really changed from the small girl she once was. Today, whenever she opens or closes a bathroom door, I laugh and remember the gap-toothed toddler whose smile would fill the entire room. The musical group The Wallflowers once sang, "The only difference, that I see, is you are exactly the same as you used to be." No matter how much she grows, she will always be the same Laura. **EP**

Submit your Children's Page to: EP, Attn: Children's Page, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number, and e-mail address! ***Now on the Web!*** We will now be including **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

A World Without Limits For Hearts That Know No Bounds

Life's A Trip – Travel In Style

Financial Assistance Comprehensive Adaptive Equipment Information

- $1,000 for the installation of adaptive equipment.[1]
- $200 for alerting devices, lumbar seats and running boards.[2]
- Solid information about selecting and installing adaptive equipment.

Ford Motor Company Products
Ford, Lincoln and Mercury cars, vans and light trucks of proven quality, durability, performance and value.

Ford Credit Mobility Financing
Flexible finance terms on both the vehicle and the adaptive equipment for qualified customers enrolled in the Ford Mobility Motoring Program.

Ford Motor Company
MOBILITY MOTORING
LINCOLN Ford Mercury

Order Your Ford Mobility Motoring Information Kit Today!

From Our Web Site:
www.ford.com/mobilitymotoring

From Our Telephone Response Center:
1-800-952-2248 or TTY 1-800-833-0312

[1] The Ford Mobility Motoring Program will reimburse for the exact amount of the adaptation up to a maximum of $1,000 on adaptive equipment and up to a maximum of $200 on alerting devices, lumbar support and running boards when you take new retail delivery of a 2001, 2002 or 2003 Ford, Lincoln or Mercury vehicle by August 31, 2002. Total reimbursement not to exceed $1,000.

[2] Factory installed air conditioning, lumbar seats, running boards and power windows options are not eligible for Ford Mobility Motoring Program assistance.

MA[illegible]

Circle #42 or visit www.eparent.com/adinfo

A Better Bedtime Story

The Vail Enclosed Bed

Once upon a time, parents of special-nee children dreamed of a way to make bedti easier and safer. With Vail Beds, everyon sleeps happily ever after. Your child enjoy the soft, non-threatening security of an enclosed hospital bed—while you enjoy pea of mind knowing they are protected durin the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for yo child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adul feature lifetime service; and come comple with mattress, manually adjustable hospit bed and vinyl border and bedskirt. Plus, we provide assistance in obtaining insurance approval.

Available from home health-care products dealers, or direct from th manufacturer.

For a FREE catalog, call: 1-800-235-VAIL

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard

Ask about Our Decorator Accessories.

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

Sheri Wittmer
Sandusky, Ohio

Vail Meadows Therapeutic Riding Center

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for challenged riders.

Circle #78 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community
PARENTS ○ FAMILIES ○ PHYSICIANS ○ PROFESSIONALS

EP
Exceptional Parent

APRIL 2002
$4.95

Sensory Integration Tips

Oral Health Procedures

Medical Research Update

SPECIAL MOBILITY SECTION

www.eparent.com

BEST COPY AVAILABLE

For people with severe spasticity due to cerebral palsy, brain injury, or spinal cord injury

There is something you can do about severe spasticity. Oral medications may help some people with severe spasticity, but for many, it may not be effective or may cause intolerable side effects. When spasticity continues to interfere with the way you live, there is something you can do about it.

ITB™ Therapy (Intrathecal Baclofen Therapy) is an effective way to control severe spasticity. A medication called Lioresal® Intrathecal (baclofen injection) is delivered directly to where it's needed most — in the fluid that surrounds the spinal cord. In clinical studies, ITB Therapy reduced spasticity during the screening test in 97%[1] of people with severe spasticity due to multiple sclerosis or spinal cord injury, and in 86%[1] of people with severe spasticity due to cerebral palsy or brain injury.

Take the first step. Find out how the therapy can work for you. Talk to your doctor about the screening test, which uses a small amount of medication to test if it will work for you. For more information call us today at 800-664-5111 Ext. 220. Or, you can log on to www.spasticity.com.

ITB Therapy drug side effects are usually temporary and manageable by adjusting the dose. The most common side effects include loose muscles, drowsiness, nausea/vomiting, headache, and dizziness. Close attention to your doctor's instructions is required since abrupt discontinuation of intrathecal baclofen can result in high fever, altered mental status, returned spasticity, and muscle rigidity, and in rare cases has been fatal. (For more information, please read the attached Lioresal Intrathecal Patient Information on the back.)

---

[1] Controlled clinical studies on file,
Medtronic, Inc.

©2002 Medtronic. Inc.

Medtronic
When Life Depends on Medical Technology

Patient Information

LIORESAL® INTRATHECAL
(baclofen injection 10 mg/5 mL, 10 mg/20 mL, 0.05 mg/1 mL)

Completely read this information before you start using Medtronic ITB™ Therapy (Intrathecal Baclofen Therapy). This information does not take the place of thorough discussions with your doctor. You and your doctor should discuss ITB Therapy before you begin receiving the therapy and at regular refill appointments.

Q: What is Lioresal® Intrathecal (baclofen injection)?

A: Lioresal Intrathecal is a liquid form of baclofen, and is commonly used to treat severe spasticity. Liquid baclofen is used for injections and infusion into the intrathecal space (the fluid-filled area surrounding the spinal cord), using an implantable drug delivery system.

Q: What is severe spasticity?

A: Severe spasticity is tight, stiff muscles that make movements – especially of the arms and legs – difficult or uncontrollable. Severe spasticity can interfere with an individual's function and/or comfort.

Q Who is a candidate for Lioresal Intrathecal?

A: People who suffer from severe spasticity resulting from cerebral palsy, multiple sclerosis, stroke, traumatic brain injury, or spinal cord injury, and who suffer intolerable side effects from oral baclofen (pills), may be a candidate for Lioresal Intrathecal. A screening test will help determine if you will respond to the intrathecal medication. Talk with your doctor about whether Lioresal Intrathecal may be an option for you.

Q: Who is *not* a candidate for Lioresal Intrathecal?

A: People who are hypersensitive (extremely sensitive) to oral baclofen should not take Lioresal Intrathecal.

Q: What are the most common side effects of Lioresal Intrathecal?

A: The side effects of intrathecal baclofen include loose muscles, sleepiness, upset stomach, vomiting, headaches, and dizziness. As with most medications, overdose (drug dose is too high) or under dose (drug dose is too low) can occur. Talk with your doctor about the side effects you may experience from your treatment.

Q: What do I need to know if I am using Lioresal Intrathecal?

A: Abruptly stopping intrathecal baclofen can result in serious medical problems and in rare cases has been fatal.

Q: What are the signs of rapid or abrupt withdrawal from intrathecal baclofen?

A: Increase or return in spasticity, itching, low blood pressure, lightheadedness, and tingling sensation are often early indications of baclofen withdrawal. It is very important that your doctor be called right away if you experience any of the above symptoms.

In rare cases, severe symptoms may occur. These symptoms include high fever, altered mental status, spasticity worse than before you started ITB Therapy, and muscle rigidity. It is very important that your doctor be called right away if you experience any of the above symptoms.

Q: What can I do to prevent baclofen underdose or abrupt discontinuation of intrathecal baclofen?

A: It is very important that you keep all of your refill appointments. This may require some planning prior to traveling. Maintaining a regular refill schedule will ensure the pump does not run out of medication and that any potential problems with the infusion system are diagnosed and corrected. Additionally, you should be aware of what your pump alarms sound like. If you hear the alarm, contact your doctor immediately.

Furthermore, it is very important that you know and understand the signs of baclofen underdose. Also be sure to tell your doctor right away if you experience any unusual symptoms, side effects, or changes in your condition.

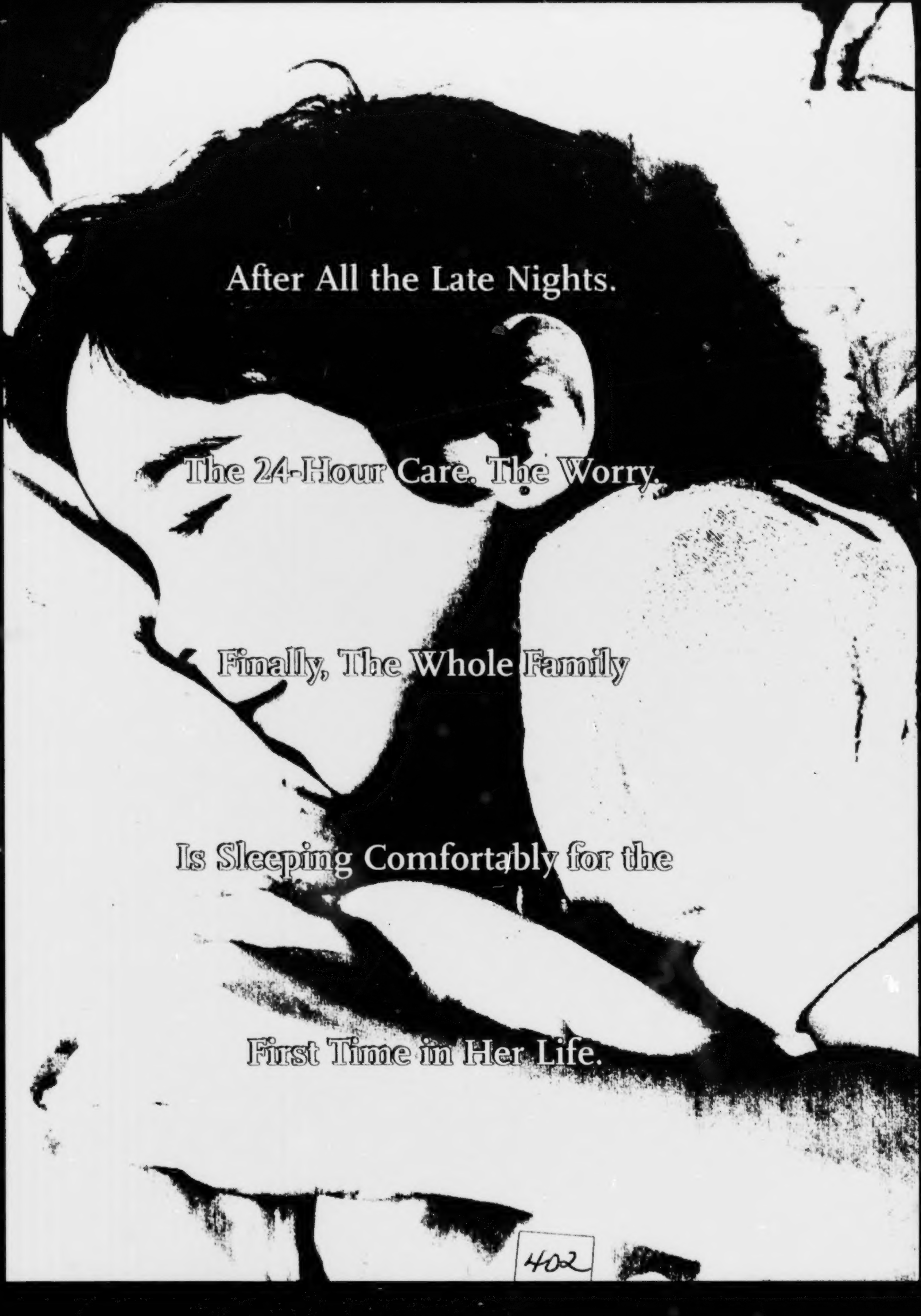
Q: What are the symptoms of baclofen overdose?

A: Although rare, it is possible for you to receive too much medication (overdose). A baclofen overdose may cause drowsiness, lightheadedness, respiratory depression (difficulty breathing), seizures, loss of consciousness and coma. If you experience any of the above symptoms, it is very important that you or your caregiver contact your doctor right away.

Rx only.

Lioresal® is a registered trademark of Novartis Pharmaceuticals Corporation.

This provides a summary of the most important information about Lioresal Intrathecal. If you would like more information, talk with your doctor. You can ask for information about Lioresal Intrathecal that is written for healthcare professionals. You also can get more information by visiting www.spasticity.com.


After All the Late Nights.
The 24-Hour Care. The Worry.
Finally, The Whole Family
Is Sleeping Comfortably for the
First Time in Her Life.

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

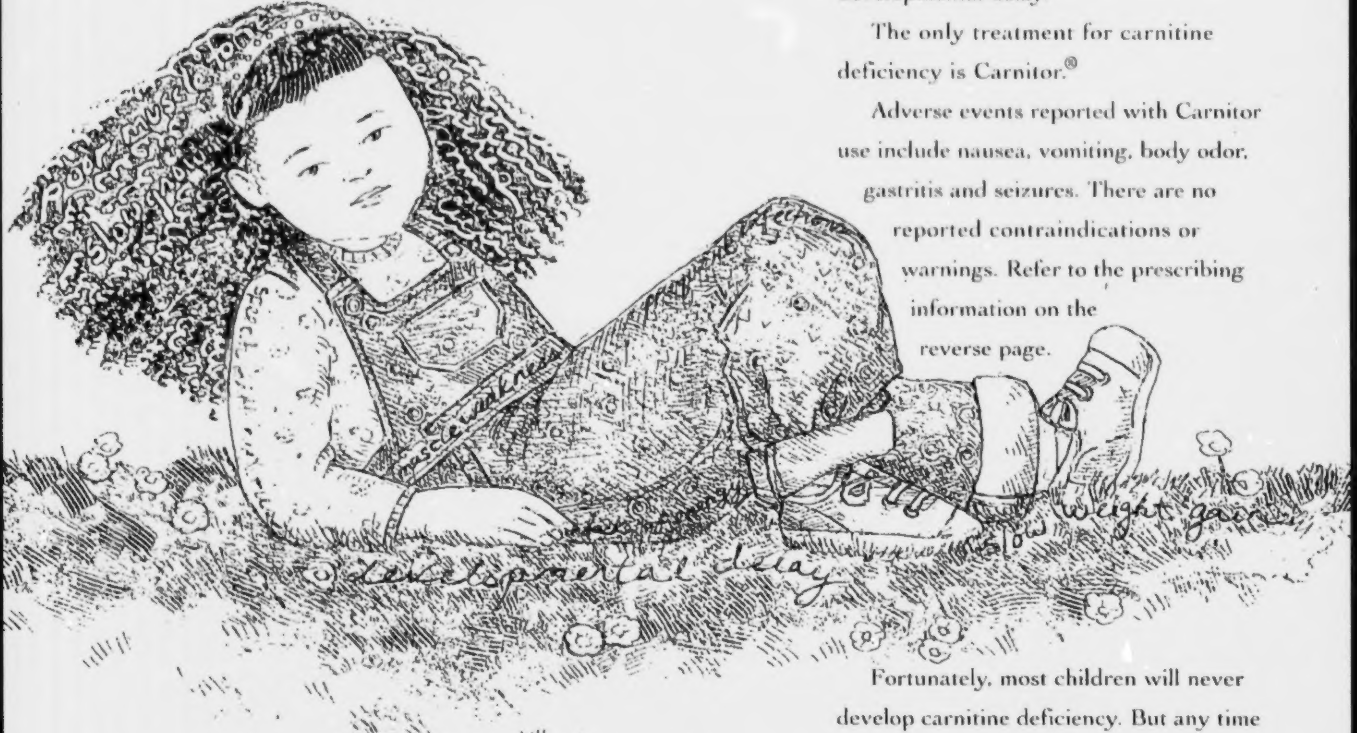
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Circle #71 or visit www.eparent.com/adinfo

Carnitor®

levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Charles C Thomas
PUBLISHER • LTD.

2600 South First Street
Springfield, IL 62704

Forthcoming releases from Charles C Thomas, Publisher!

COMMON TERMINOLOGY, ABBREVIATIONS AND SYMBOLS FOR THERAPEUTIC RECREATION AND OTHER ACTIVITY THERAPIES
A Glossary and Workbook
To be published 2002, 160 pages
David L. Jewell
$23.95, paper ISBN 0-398-07266-3

ENDING DISCRIMINATION IN SPECIAL EDUCATION
(2nd Ed.)
To be published 2002, 150 pages
Herbert Grossman
paper, ISBN 0-398-07304-X

HOW WE SEE GOD AND WHY IT MATTERS
A Multicultural View Through Children's Drawings and Stories
Published 2001, 230 pages
Robert J. Landy
$58.95, hard ISBN 0-398-07170-5
$41.95, paper ISBN 0-398-07171-3

EVALUATION AND EDUCATIONAL PROGRAMMING OF STUDENTS WITH DEAFBLINDNESS AND SEVERE DISABILITIES
Sensorimotor Stage (2nd Ed.)
Published 2001, 294 pages
Carroll J. Jones
$45.95 paper ISBN 0-398-07216-7 (displayed)

EXCEPTIONAL LEARNERS
Education and Research from a Global Perspective
Published 2001, 260 pages
Ivan Z. Holowinsky
$59.95, cloth ISBN 0-398-07163-2
$38.95, paper ISBN 0-398-07164-0 (displayed)

EDUCATIONAL INTERVENTIONS AND SERVICES FOR CHILDREN WITH EXCEPTIONALITIES
Strategies and Perspectives (2nd Ed.)
Published 2001, 304 pages
George R. Taylor
$66.95, cloth ISBN 0-398-07112-8
$44.95, paper ISBN 0-398-07113-6 (displayed)

AUTISM AND POST-TRAUMATIC STRESS DISORDER
Ending Autistic Fixation
Published 2000, 136 pages
Kenneth Lenchitz
$36.95, cloth ISBN 0-398-07096-2
$19.95, paper (displayed) 0-398-07097-0

HOME IS WHERE THE ART IS
An Art Therapy Approach to Family Therapy
Published 2001, 224 pages
Doris Banowsky Arrington
$61.95, hard ISBN 0-398-07160-8
$42.95, paper ISBN 0-398-07161-6

DEVELOPING AND IMPLEMENTING IDEA-IEPs
An Individualized Education Program (IEP) Handbook for Meeting Individuals with Disabilities Education Act (IDEA) Requirements
Published 2001, 274 pages
Edward Burns
$59.95, hard ISBN 0-398-07122-5
$40.95, paper ISBN 0-398-07123-3 (displayed)

RESEARCH IN SPECIAL EDUCATION
Designs, Methods, and Applications
Published 2001, 268 pages
Phillip D. Rumrill, Jr., & Bryan G. Cook
$56.95, cloth ISBN 0-398-07172-1
$38.95, paper ISBN 0-398-07173-X (displayed)

Programmed Therapy FOR STUTTERING in Children and Adults (2nd Ed.)
Published 2000, 360 pages
Bruce P. Ryan
$79.95, hard ISBN 0-398-07106-3
$54.95, paper ISBN 0-398-07107-1

SPECIAL EDUCATION, MULTICULTURAL EDUCATION, AND SCHOOL REFORM
Components of Quality Education for Learners with Mild Disabilities
Published 2000, 280 pages
Cheryl A. Utley & Festus E. Obiakor
$63.95, hard ISBN 0-398-07118-7
$41.95, paper ISBN 0-398-07119-5

Contact us to order books or a free catalog with over 811 titles

Call 1-800-258-8980 or 1-217-789-8980 or Fax 1-217-789-9130
Complete catalog available at www.ccthomas.com • books@ccthomas.com

Books sent on approval • Shipping charges: $6.95 U.S. / Outside U.S., actual shipping fees will be charged
Prices subject to change without notice

Circle #25 or visit www.eparent.com/adinfo

contents

APRIL 2002 ◦ VOLUME 32, ISSUE 4

MEDICAL RESEARCH UPDATE

20 **Issues and Trends in Treatment of Children with Autism Spectrum Disorders**
by Betsy Weaver, EdD, with Miranda Hersey
The latest in what's going on in the field.

26 **Pedaling with Pete: One Man's Journey to Raise Awareness About Cerebral Palsy**
by Anne Kirkland
Role Model Pete Zeidner rides to improve research despite personal challenges.

56 **NIH Update: National Human Genome Research Institute and the National Institutes of Health Office of Rare Diseases Launch New Genetic and Rare Diseases Information Center**
Submitted by The Genetic and Rare Diseases Information Center

116 **Research Reflections SSI and Employment Opportunities for Young Adults with Retardation: Safety Net or Bungee Cord?**
by Jan Blacher, PhD
What SSI is, who qualifies for it and how to get it.

FEATURES

34 **On the Move**
by Siskin Children's Institute
The nonprofit Siskin Children's Institute offers learning and play for children of all ages and developmental levels.

42 **Parent Perspective: A December to Remember**
by Frances Ficocelli
One family's success in finding the best learning environment for their son.

47 **An Introduction to: Early Childhood Sensory Integration**
by Carolyn O. Cantu, MS, OTR
Some background on sensory integration issues in young children and tips for therapy.

60 **A Child's Self-Statement: Who Am I?**
by Corinne G. Catalano, MA, Purnima Rathi Hernandez, DDS, MA, Patty Wolters COTA
Creating a profile from your child's perspective.

113 **The Use of Sedation for the Dental Patient with Special Needs**
by Nancy Dougherty, DMD, Maureen Romer, DDS, MPA and Steven P. Perlman, DDS, MScD
There are many situations where sedation can be helpful in providing good dental care.

MOBILITY
SPECIAL ADVERTISING SECTION
PAGES 70-99

BEST COPY AVAILABLE

COVER: Though Pete Zeidner has battled cerebral palsy since childhood, his disability has not kept him from his passion for biking. Here he is pictured on the recumbent bike adapted for his riding needs. Through his nonprofit organization, The Pedal with Pete Foundation, based in Kent, Ohio, Pete organizes bike & hike-a-thons that help raise money for CP research. See page 26 for the story. Photo by Robert J. Lucas.

EP
Exceptional Parent

contents

DEPARTMENTS

10 Editor's Desk

12 Search & Respond

66 Familiar Faces

67 Ask The Therapist

- Moving Toward Mobility: Building skills and improving health by integrating a range of seating and transport options
  by Ginny Paleg, MS, PT

100 What's Happening

- Southern California Moms "Jump" at the Chance to Help Kids with Disabilities

102 Book Notes

- "Raising a Child with Autism" Reviewed by Marianne Taylor

103 Organizational Spotlight

- National Alliance for Autism Research
  Committed to Accelerating Biomedical Autism Research to Unlock the Mysteries of Autism Spectrum Disorders

110 EP Library

120 New Products

124 Children's Page

- "Train of Thoughts"
  by Carlie Grippi

EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTH-CARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy-Ed Corp., dba *EXCEPTIONAL PARENT Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy-Ed Corp. *EXCEPTIONAL PARENT*® is a registered trademark of the Psy-Ed Corp. **Postmaster:** Please send address changes to: *EXCEPTIONAL PARENT*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *EXCEPTIONAL PARENT*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *EXCEPTIONAL PARENT*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #1420542. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

EXCEPTIONAL PARENT neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
While hyperbaric oxygen is effective therapy in certain conditions it is currently considered an alternative therapy for CP and other "brain insult" conditions. Readers are advised to discuss the advisability of HBOT with their primary or specialty healthcare providers as well as to study the current literature.

—Rick Rader, MD

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

MITCHELL F. BRIN, MD, Vice President, Botox, Allergan, Irvine, CA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics, Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof. Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

HARILYN ROUSSO, ACSW, Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

THERESA VARNET, MSW, JD, Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

408

ORIGINAL
EDENSOY
ORGANIC SOYMILK
EDEN.
33.8 FL OZ (1.06 QT) 1 LITER
peace of mind

A Great Idea, Made the Right Way

EDENSOY® provides up to 11 grams of soy protein per serving (twice that of most soymilk) so it's easy to get the FDA suggested 25 grams per day for heart health. Made of whole food ingredients like organic non-genetically engineered bean and grain; EDENSOY has absolutely no refined sugar, undeclared soy isolate or flavor masking ingredients, with 5.67% more than a quart in our liter. America's first soymilk and still the best, EDENSOY.

EDEN®

www.edenfoods.com

©2002 Eden Foods, Inc., Clinton, Michigan 49236 888-424-EDEN

Circle #34 or visit www.eparent.com/adinfo

parve

MANUFACTURER'S COUPON | EXPIRES 08 / 31 / 02

50¢ Off Any EDEN® Soymilk 1 Liter or multi-pack

Consumer: Coupon good only in USA on purchase of brands / size indicated. Void if copied, transferred, prohibited or regulated. **Retailer:** Eden Foods, Inc will reimburse you for the face value of this coupon plus 8¢ handling if redeemed in compliance with our redemption policy. Copy sent upon request. Invoices proving purchase of sufficient stock to cover coupons must be shown on request. Face value .001¢. Mail coupon to **CMS Dept. #24182; One Fawcett Drive; Del Rio, Texas 78840**

Expires: August 31, 2002 **10646**

5 24182 00050 9 (8102) 00

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration #01-911713

Circle #18 or visit www.eparent.com/adinfo

EP

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

EDITOR-IN-CHIEF Rick Rader, MD
MANAGING EDITOR & VP OF MEDICAL EDUCATION Fern R. Potvin
EDITOR Natalie E. Gerber, PhD
EDITORIAL/MARKETING INTERN Christina E. Spatz
EDITORIAL INTERN Megan Henninger
INFORMATION SYSTEMS COORDINATOR Dennis Dusevic
RESEARCH ASSISTANT Susan Jenkins
GRAPHIC CONSULTANT Dennis Wilkes

PRESIDENT, CEO & PUBLISHER Joseph M. Valenzano, Jr.
VP BUSINESS DEVELOPMENT & INTERNET PROJECTS Vanessa B. Ira
VP ORGANIZATION RELATIONS & CONSULTING EDITOR Bridget M. Lyne
CHIEF FINANCIAL OFFICER Dolores A. Kinley
AD TRAFFIC MANAGER Kendra Kelly
SALES COORDINATOR Doris DeFina
RECEPTIONIST/PUBLIC RELATIONS COORDINATOR Robyn Sager
ART DIRECTION, DESIGN Publishers Design Group, Inc
✉ annpdg@aol.com
PRODUCTION MANAGER Michael Longobardi
EP LIBRARY Ron Richards
(800) 535-1910
✉ eplibrary@aol.com
WEBMASTER Ken Fleischer, Dynamic Media Works
✉ webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Jared F. Adams
EASTERN REGION:
(CT, ME, NH, NJ, NY, RI, VT)
✉ jadams@eparent.com
(201) 489-4111,
FAX: (201) 489-0074

Barbara Nastro
SOUTHEAST REGION:
(AL, AR, DC, DE, GA, FL, MD, MS, NC, PA, SC, VA, WV)
SCHOOLS, CAMPS, RESIDENCES & CLASSIFIED
✉ nastro@blast.net
(908) 534-6366
FAX: (908) 534-6941

Annabelle and Gabe Jacobson
MIDWEST REGION:
(IA, IL, IN, KS, KY, MI, MN, MO, NE, ND, OH, OK, SD, TN, WI)
AUTOMOTIVE
THE LYON GROUP
✉ bellyon@megsinet.net
(847) 256-6850
FAX: (847) 256-6819

Larry Battistello
WESTERN REGION:
(AK, AZ, CA, CO, HI, ID, LA, MT, NM, NV, OR, TX, UT, WA, WY)
Marketing Plus
✉ seeme4ads@aol.com
(760) 320-8797
FAX: (760) 320-9728

Vanessa B. Ira
MASSACHUSETTS & INTERNET AD SALES
✉ vieprnt@concentric.net
(201) 489-4111, ext. 209
FAX: (201) 489-0074

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

PUBLISHING & EDITORIAL OFFICE
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

SUBSCRIBER SERVICE:
EXCEPTIONAL PARENT
P.O. Box 2078, Marion, OH 43306-2178.

CUSTOMER SERVICE/NEW ORDERS:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

EXCEPTIONAL PARENT magazine was founded in 1971 by Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 106

Imagine...

if all of your other
choices could be this simple

MOTOR COMPANY INC LIBERTY

Introducing a
zero
maintenance
conversion van with wheelchair access

BEST COPY AVAILABLE

Starting Under
$20,000 US
(Including vehicle and modification)

- 1996-2002 Windstar Models Available (All vans come with brand new conversions)
- Professionally trained staff ready to help you
- The rear-entry design provides for the safest and most reliable wheelchair accessible minivan on the market.
- The Liberty Motor Co modified Ford Windstar looks and drives like a standard minivan, offering a quiet, comfortable ride.
- Money Back Guarantee

Circle #55 or visit www.eparent.com/adinfo

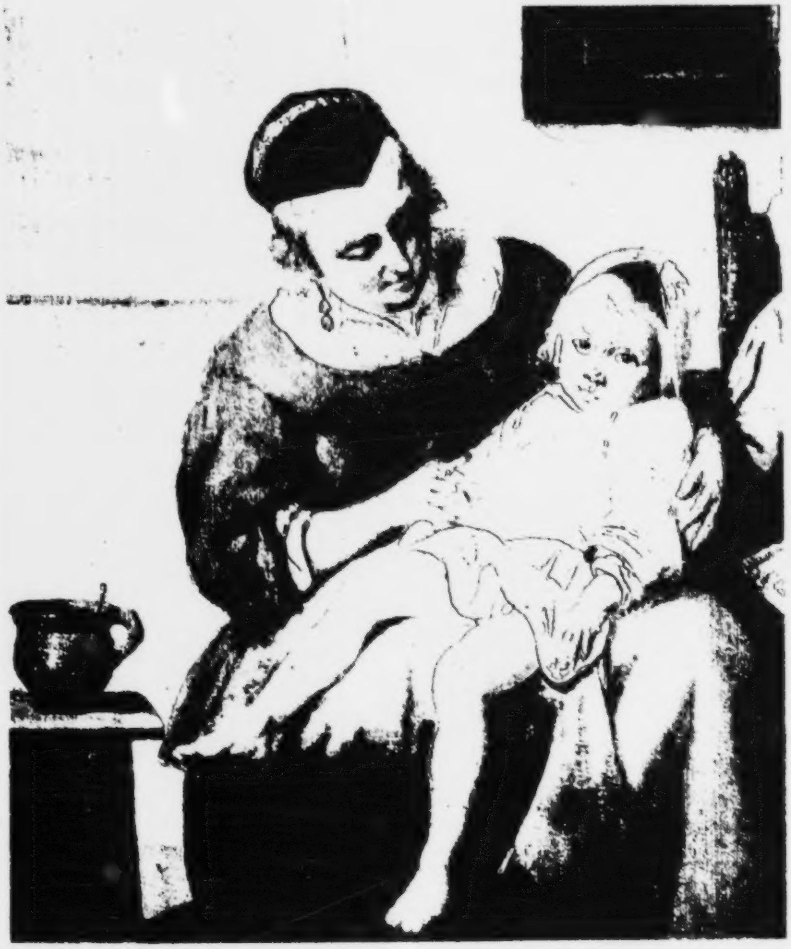
1 (888) 578-8886 www.libertymotorco.com

At a Nurses' Station at Great Ormond Street

They say a picture is worth a thousand words, and that's what I am normally allotted for my monthly *Editor's Desk*. When I was a med student, I did a rotation at London's famed Hospital for Sick Children at Great Ormond Street. At one of the nurses' stations, where the students would stock up on Cadbury's chocolate taken from patients' rooms and read charts, there was a crude wood sign with the quote that appears below. It is, in essence, this month's Editor's Desk. On the last day of my rotation I scribbled it down on the back of a wrapper from a Fruit and Nut Bar, and have kept it ever since. EP Magazine has provided this picture for you with our compliments. It's suitable for framing, or tearing out and mailing to your doctor a week before your next visit. EP

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN



"An observant parent's evidence may be disproved but should never be ignored"
—Lancet 1:688, 1951, Anonymous

Clay, Danny, Robin and Danielle Wagner live in Fort Lauderdale, Florida. Clay is autistic and has a seizure disorder.

"We're a PediaSure® Family."

"PediaSure helps us give Clay the nutrition he needs."

All kids need proper nutrition for growth and development. If your child is not getting enough of the right nutrition from regular food or has special feeding needs, ask your doctor about the complete, balanced nutrition of PediaSure. It's specially formulated to provide children with proper amounts of protein, fat, carbohydrate, vitamins and minerals. Available in your local supermarket, drug or discount store.

PediaSure
Pediatrician Recommended
Lactose Free

Available through WIC®*

*If your child has special dietary needs, check with your physician or local WIC clinic to see if your child is eligible to receive PediaSure through the WIC program. WIC is a registered trademark of the U.S. Dept. of Agriculture.

© 2001 Abbott Laboratories

Circle #69 or visit www.eparent.com/adinfo

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our Web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

Instant S&R

S

Visual Learning Disability

My son was just diagnosed with a visual learning disability. I was told that he has a problem "processing" the information he is receiving visually. He is 4 1/2 years old and attends a regular preschool. His teacher noticed that he was not retaining things that were being taught visually (alphabet, numbers, etc.). He is extremely bright and thinks on an abstract level which is why the teacher became suspicious. Can anyone tell me what is in store? What therapy or strategies might we try to help him compensate? Any advice would be helpful.

—123 Via EP web site

R

I'm a parent advocate specializing in educational law. I would suggest that you look into several things: 1. Ask for a very clear definition of visual processing disability. The label is not enough information to lead you to the treatments that will be necessary. For example, is it a problem of visual discrimination, visual sequencing, visual memory? Each is different regarding the process that information must go through when it enters the brain. 2. Do you know if your child has visual acuity problems? 3. Find out if your son's auditory processing is intact. If so, you can use that route of input to help him build visual processing. For example, try singing the ABCs to add auditory input while he is looking at the letters. 4. Ask for special education services (ultimately an IEP). Make sure that your son receives school-based accommodations, modifications and specially designed instruction at no cost to you. 5. Ask for multi-sensory instruction.

—Hope, iepvic@aol.com,
Via EP Web site

Abbreviations Used in this Month's S&R:

- GI = gastrointestinal (esophagus, stomach, small and large bowels)
- G-tube or GT = gastrostomy feeding tube, inserted through the skin into the stomach
- IEP = individual educational plan

S

Pelizaeus-Merzbacher, Gastrostomy Tube, and Quality of Life

We have a 2-year-old son who has been presumptively diagnosed with Pelizaeus-Merzbacher brain sclerosis (a progressive disease of the central nervous system affecting the brain's white matter). He is experiencing severe developmental delays (does not hold up his head) and feeding issues stemming from his hypotonia, along with congenital nystagmus. He is failing to thrive, weighing in at 18 pounds and measuring 30 inches. We are currently in the hospital for pyloroplasty surgery (to amend delayed gastric emptying) and the placement of a g-tube. We are not familiar with the quality of life and the potential we can expect him to display. We are certainly interested in providing him every opportunity to excel. We are looking for anyone else who has this disease, any information that can be provided about the surgeries mentioned, and therapies, activities, facilities or toys which can help us give him what he needs and deserves.

—Jennifer Seman,
semanalex@aol.com, Via EP Web site

R

My son is 25 and has had a g-tube since he was 8. I have worked in special education for 13 years and have had a number of students with g-tubes and three godchildren with them also. At the point of having a surgery done, my first rec-

Continued on page 14

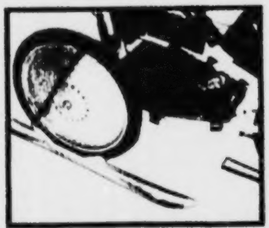
Informed Parents

Where Parents Keep Up To Date On Products For Their Children's Special Needs

The Kangoo
Bike Trailer Option

FUN Fact

With the Kangoo's multiple functions, this unit can go with you anywhere from a city street walk to a mountain bike ride, to a cross country ski adventure!



Snow Ski Option

SunScreen Option

Standard Rehab Stroller
Complete line of positioning accessories available

Car Seat Option Coming Soon!

Swivel Front Wheel Option

Information / Free Catalog CD Rom

1-800-336-7684 snugseat.com

VISA

SNUG SEAT®

4/5

Circle #72 or visit www.eparent.com/adinfo

Search & Respond

Continued from page 12

ommendation is to make sure an emptying study is done, in the event that a g-tube fails. At the same time, a pyloroplasty may be done if needed. Next, after some healing has taken place (usually a Foley tube is inserted with the surgery) use a MicKey g-tube, it is much easier and will not tangle as much.

I am surprised at the number of doctors I have met unfamiliar with these products and their use, even those who specialize in gastrointestinal procedures. We have to stay on top of new items and maintenance techniques. I have had to learn through trial and error. But Jason is healthy and a g-tube has been one of his best quality-of-life procedures. He can still eat and enjoy all of the good stuff by mouth, while medications and nutrition are taken care of via his g-tube. He also enjoys sleeping in for breakfast and gets breakfast in bed. Also, the g-tube is a blessing on trips, since we can now feed him in the car while going down the road. All this, and choking and aspiration have been minimized, too.

—Debra Marasco-McNulty
via EP Web site

Editor's Note: You might also want to visit the Pelizaeus-Merzbacher Disease Foundation Web site, and particularly their parent page, at http://www.pmdfoundation.org.

Information About Children with Tracheotomies

I would like to see more information about children with tracheotomies. There are many reasons why children have trachs, but trach care is basically the same for all. I don't know whether there is a national support group, which would be very helpful to many families.

—152 via EP web site

There is a web site devoted to children with tracheotomies, at http://tracheostomy.com. This site is a wealth of information! There is a link on that page to "Kids with Tracheostomies," with many photos and stories. My daughter is on Page 2, Clara Grace Chilton, though her story is very out-of-date. She is now 4 years old, has already had her heart surgery, and still has her trach. There is also a "networking" link that lists several e-mail lists that you can join along with chat rooms or message boards. Good luck!

—1170 via EPWeb site

Editor's Note: The terms "tracheostomy" and "tracheotomy" are often used interchangeably, and, although the technical differences between the two are not really that important, most children have tracheotomies.

Search

Partial Trisomy 7q

A friend of mine has an 8-month-old daughter who has been diagnosed with partial trisomy 7q. My friend has been unable to find any information or support pertaining to this specific disorder. She would especially love the chance to talk with some "been there, done that" parents.

—141 via EP Web site

Lung Problem

My 3-year-old was diagnosed with bronchitis three weeks ago. He didn't respond well to treatment, so we did a chest X-ray. He has pneumonia and the doctor says he has asthma, too. He had pneumonia when he was 16-months-old (possibly for some time before that). It was accidentally found during an upper GI test to follow up on his gastroesophageal reflux. It took many bottles of antibiotics to clear up that infection. It seems like his lungs are just taking a beating. Could there be another underlying problem that could be causing all of his colds, bronchitis, pneumonia, etc.? He seems to have had trouble breathing and growing from birth. I really worry about his lack of immunity to illnesses.

—130 Via EP web site

Childcare

We are the parents of a 14-month-old girl with global developmental delay, seizure disorder and feeding issues (all liquids through g-tube). We are having a tough time finding appropriate child care for her and prefer in-home care. We have already been through one nanny who took advantage of her special needs by ignoring her (much to our horror and dismay). We have cobbled together care from friends and have a temporary nanny. I am told we do not qualify for any benefits to aid in deferring the cost of the care. In addition, how do we find the right kind of committed individual? Both my husband and I must work. Any suggestions (especially from those of you in Pennsylvania)?

—Molly Watson, via EP Web site

Editor's Note: Medicaid waivers exists in some states which can help parents care for their child at home. Parent Training and Information centers (PTIs) can provide information on those programs. For PTIs in each state, contact the PACER Center (888) 248-0822. In Pennsylvania, contact the Parent Education Network (800) 522-5827 to find out if your family can qualify for the waiver.

Selective Neurectomy

Our 5-year-old son has spastic cerebral palsy. He has been evaluated for selective dorsal rhizotomy and found not to be a good candidate. The doctor has discussed the possibility of a selective neurectomy. Has anyone had this done on their child, and what were the results, esp. in terms of a reduction in tone and an increase in their ability to perform activities of daily living?

-Cathy Buckley, Floral Park, N.Y

Respond

Difficulty with Gastrostomy Tube

In the February 2000 issue, SH has a 7-year-old grandchild who had discomfort and other problems with his gastrostomy tube (GT), which needs continuous venting.

We have had many feeding difficulties and have tried many things to help our son stay vented, especially during therapies. Our surgeon came across a new product that has been wonderful. The bags will fit any feeding method. It is called a Farrell Valve System for external gastric pressure relief. We were the first to use these at our children's hospital. We call them burp bags. These are made by Corpak MedSystems, Inc ([800] 323-6305). We were unable to get our insurance to pay for this new product initially but now they are being covered. Our GI specialist was not familiar with them but is now using them successfully with other children.

—JR via e-mail

4,6

DON'T MISS OUT!!!

5TH INTERNATIONAL UMDF SYMPOSIUM ON MITOCHONDRIAL DISEASE

JUNE 6-9, 2002

WESTIN GALLERIA, DALLAS, TX

This informative weekend for Mitochondrial Specialists, Clinicians and Families promises to be the best UMDF conference yet! Register NOW!

UMDF Rekindling Hope

UNITED MITOCHONDRIAL DISEASE FOUNDATION

SOUTHWESTERN

For more information on the Dallas 2002 Symposium or UMDF membership, please contact the UMDF office at 412-793-8077, info@umdf.org or visit www.umdf.org.

Please mail the form below to:

The United Mitochondrial Disease Foundation
8085 Saltsburg Road, Suite 201
Pittsburgh, PA 15239

Contribution Form and Request for Information

- ☐ Please send me ____ registration forms for the **5th International Symposium in Dallas**
- ☐ Please send me information about Mitochondrial Disease and UMDF membership
- ☐ Enclosed is my gift to help sustain research and family support: $ ____________

■ **Note: UMDF members pay a lower registration fee for the UMDF Symposium**

(Please make checks payable to UMDF)

The above gift is made: ☐ *In Memory of* ☐ *In Honor of*

Name ______________________________

On the occasion of: ______________________ *(Memorial, birthdate, deathdate, other)*

Please send an acknowledgement of my gift to:

Name: ______________ Address: ______________

City: ______________ State: ______________ Zip: ______________

Please supply us with your information to send a packet and to acknowledge your gift:

Name: ______________ Address: ______________

City: ______________ State: ______________ Zip: ______________

UMDF also accepts ☐ Visa or ☐ Mastercard ______________________

(card number)

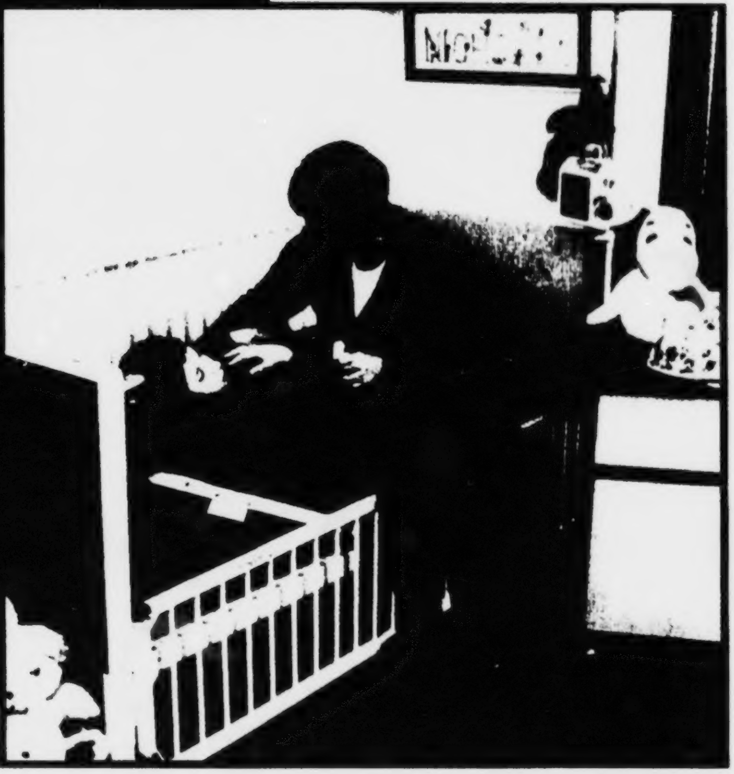
Name as listed on card (print): ______________ Signature of Cardholder: ______________

Gifts to UMDF are tax-deductible.

HARD MANUFACTURING

AGE APPROPRIATE BEDS

For when your child passes the crib stage!



Dianna Fitzgerald
& Her Son Nicholas

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

The Stockton features full crib safety sides

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #46 or visit www.eparent.com/adinfo

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C.
& Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #56 or visit www.eparent.com/adinfo

Issues and Trends

in Treatment of Children with Autism Spectrum Disorders

By Betsy Weaver, EdD, with Miranda Hersey

Autism and its associated spectrum of disorders are severe disorders of communication and social relatedness. It is estimated that more than two out of every 1,000 children in the United States are affected by autism or autism spectrum disorders (ASD), and, according to a recent study by the Centers for Disease Control and Prevention (CDC), that number may be as high as six per 1,000. This means there are at least 1.5 million children and adults with autism in America, making it one of the country's most common developmental disabilities.

Our understanding of these disorders has changed radically over the past few years and has attracted media attention. The changes include a redefinition of the disorder, a measurable rise in prevalence and breakthroughs in treatment. There is a new emphasis on early diagnosis and intensive intervention, both of which can markedly change outcomes. Other recent issues include the availability of qualified therapists and the scrutiny of treatment cost and concentration.

Despite the increase in media interest and the expansion of treatment options, there are few information resources for families needing help with the ASD treatment process. Parents and children navigating treatment decisions are faced with conflicting information, sometimes controversial therapies, and the lack of specialized therapists and support networks. When these hurdles are overcome, however, and appropriate therapy is carried out, treatment is more likely to have a positive outcome.

> **...in addition to figuring out what is best for the child, keep in mind what will work best for you as parents as well.**

Earlier diagnosis

Treatment options for ASD have evolved significantly in a relatively short amount of time. Only 20 years ago, the vast majority of people with autism were eventually institutionalized. For decades, autism was treated with psychoanalysis. Today, ASD is commonly regarded as a neurobiological disorder and treatment is based on behavioral, cognitive-developmental and medical research findings.

Diagnosing children at younger ages is an important factor in the proliferation of treatment options. In the past, children with autism spectrum disorders were diagnosed when they were between 5 and 10 years of age; treatment programs were less refined and less effective. Reaching these children earlier, at 24 to 36 months old, increases treatment effectiveness.

In July 2001, the Committee on Educational Interventions for Children with Autism (CEICA) issued a report outlining an interdisciplinary approach to education for children with autism called Educating Children with Autism (ECA), which can be read at http://www.nap.edu. Catherine Lord, PhD, professor of psychology at the University of Michigan and director of the university's Autism and Communication Disorders Center, heads CEICA. "Autism affects very basic aspects of social development and communication," says Lord. "Therefore, early intervention may help prevent the development of more severe problems, a common occurrence which begins when a child participates in early and minimal social relations. Consequently, the press for early recognition and intervention can be likened to the need for early screening for visual or hearing impairments—but instead of getting a child glasses or a hearing aid, what we're trying to do is give children with ASD intense, positive social and communicative experiences that allow them to learn and develop as well as possible. It wouldn't be accurate to say that there's a true critical period or one correct treatment. We're trying to provide kids with 'social scaffolding' to learn as other children do."

Which approach to use?

Of the numerous treatment approaches currently practiced, some of the most well known include: applied behavioral analysis

(ABA); treatment and education of autistic and related communication handicapped children (TEACCH); and the developmental, individual-difference, relationship-based (DIR) approach, often described as Floortime or the Greenspan approach. Each of these methods has documented success through case reports or research. Most programs are highly structured and individualized.

Nancy Wiseman is president of First Signs, the nonprofit organization she founded to educate physicians and parents on the early warning signs of autism and other developmental disabilities. Her daughter Sarah has ASD. Wiseman suggests that a parent's first step in the treatment process is to evaluate which particular methodology is most appropriate, with as much professional insight as possible. "Deciding which treatment or combination of treatments is best for your child depends upon the child's needs, what you can find nearby, what will be supported by those who will fund the treatment, and what feels best to you as a family. Keep in mind that no matter what anyone suggests, there is no single best approach."

Another criterion for making this decision is the level of parental involvement in treatment. As reported in ECA, "Nearly all empirically-supported treatments…include a parent component and most research programs used a parent-training approach." Therefore, in addition to figuring out what is best for the child, keep in mind what will work best for you as parents as well.

> **A surge of uncertainty goes through your head frequently when you have a child with complex problems, but you can't help your child if you are overwhelmed.**

What next?

The next step is to determine the source of funding for treatment and to resolve what other ancillary support or treatments the child needs. There are a host of therapeutic, biomedical and support services that your child may need in concert with the overall intervention approach, such as occupational therapy (OT), physical therapy (PT), speech and language therapy, play therapy, social skills groups, auditory integration therapy, Picture Exchange Communications Systems (PECS), nutritional or dietary interventions. Depending upon your child's age, some of these services may be provided by an early intervention program, for children under 3 years old, or by the public school special education department for children 3 years of age or older. Complementary therapies may or may not be part of your child's program. For children under 3-years-old, early intervention programs generally include OT, PT, speech, PECs, and social skills groups. "Additionally, you may want to consider some local community programs that provide an opportunity for social interaction, like a playgroup, sports activity or art class," Wiseman notes.

Who helps make these decisions?

Many families are daunted by the decision-making process. It is therefore key to assemble as strong a team of professionals and support network as possible. Finding professionals you can trust is paramount, Wiseman suggests. "You want people who will see your child as an individual; people who will advocate for programs to meet particular needs rather than taking a cookie-cutter approach."

It is extremely useful to have one professional on your team act as the family/child service coordinator. The specialist who diagnosed your child can often take this role, or perhaps your pediatrician or trusting educator. It's critical to involve someone who knows your child well, can act as a liaison and, equally important, be a support to you and your family. You are your child's best advocate, but you also need time to be a parent to your child and designate someone else to coordinate the complexities of a program with multiple components and service providers. When it's not possible to find a coordinator – which happens all too often, especially in areas with limited treatment resources – coordination falls to a parent. In these cases, the parent needs as much personal support as possible.

The updated Individuals with Disabilities Education Act (IDEA '97) mandates family supports and service coordination for families of children under the age of 3 with disabilities. Educating Children with Autism recommends that this coordination support be extended to children through age 8.

Shortage of qualified providers

"Personnel preparation remains one of the weakest elements of effective programming for children with autistic spectrum disorders and their families.…Ways of building on the knowledge of teachers as they acquire experience with autistic spectrum disorder, and ways of keeping skilled personnel within the field, are critical," reports ECA.

Particularly with young children, ASD treatments are intensive and often require many hours per week in one-on-one sessions. Lord explains, "In our report, we recommended 25 hours of planned intervention per week, which would include some one-on-one treatment in most cases, but also, depending on the needs of the child, could include participation in different therapies or educational programs. Some children, however, may need even more hours of individual or group treatments, again

continued on page 22

Resources and Organizations

TASH (The Association of Persons with Severe Handicaps)
http://www.tash.org/
29 West Susquehanna Ave., suite 210
Baltimore, MD 21204
410-828-8274
Advocacy group that works toward school and community inclusion of children and adults with disabilities. Provides information and referrals for services, publishes a newsletter and journal.

The Autism National Committee
http://www.autcom.org/
437 Elm St.
Kingston MA 02364-1805
Contact: Roz Forsyth
781-585-0903
Organization for the protection and advancement of the human rights and civil rights of all persons with autism and related differences of communication and behavior. Publishes *The Communicator*, provides referrals, and sponsors an annual conference.

Autism Research Institute
http://www.autism.com/ari/
4182 Adams Ave.
San Diego, CA 92116
619-281-7165
Publishes quarterly journal, *Autism Research Review International*. Provides up-to-date information on current research.

Autism Society of America, Inc.
http://www.autism-society.org/
301-657-0881 or 800-3-AUTISM
Provides a wide range of services and information to families and educators. Organizes a national conference. Publishes *The Advocate*, with articles by parents and autism experts. Local chapters make referrals to regional programs and services, and sponsor parent support groups. Offers information on educating children with autism, including a bibliography of instructional materials for and about children with special needs.

Centers for Disease Control and Prevention
http://www.cdc.gov/ncbddd/dd/ddautism.htm
770-488-7150
The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the CDC seeks to promote optimal fetal, infant, and child development; prevent birth defects and childhood developmental disabilities; and enhance the quality of life and prevent secondary conditions among children, adolescents, and adults who have a disability.

The Council for Exceptional Children
http://www.cec.sped.org/
1110 North Glebe Rd., suite 300
Arlington, VA 22201
888-CEC-SPED
Professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted.

Cure Autism Now (CAN)
http://www.canfoundation.org/
5455 Wilshire Blvd., Suite 715,
Los Angeles, CA 90036
323-549-0500
888-8AUTISM
fax: 323-549-0547
Serves as an information exchange for families affected by autism. Founded by parents dedicated to finding effective biological treatments for autism. Sponsors talks, conferences, and research. Offers workshops for parents and professionals.

First Signs, Inc.
http://www.firstsigns.org
P.O. Box 358
Merrimac, MA 01860
978-346-4380
Nonprofit organization dedicated to the education of physicians and parents in the early warning signs of autism and other developmental disabilities.

National Alliance for Autism Research (NAAR)
http://www.naar.org/
414 Wall Street, Research Park
Princeton, NJ 08540
888-777-NAAR or 609-430-9160
Dedicated to advancing biomedical research into the causes, prevention, and treatment of autism spectrum disorders. Sponsors research and conferences.

National Institute of Mental Health
http://www.nimh.nih.gov/publicat/autism.cfm
6001 Executive Blvd., Rm. 8184,
MSC 9663
Bethesda, MD 20892
301-443-4513; TTY 301-443-8431
Federal agency that conducts and supports research on mental and brain disorders, including autism. NIMH is part of the National Institutes of Health (NIH), the federal government's primary agency for biomedical and behavioral research.

Office of Special Education Programs
http://www.ed.gov/offices/OSERS/OSEP
Office of Special Education and
Rehabilitative Services
US Department of Education
400 Maryland Ave., SW
Washington, DC 20202
202-205-5507; TTY 202-205-5637
The US Department of Education's Office of Special Education Programs helps states carry out their responsibility to provide to all students with disabilities a free, appropriate public education in the least restrictive environment. These responsibilities are spelled out in IDEA/IDEA '97.

Yale Child Study Center
http://info.med.yale.edu/chldstdy/autism/
230 South Frontage Road
New Haven, CT 06520
Fax: 203-737-4197
Offers comprehensive, multidisciplinary evaluations for children and adults with social disabilities, usually focusing on the issues of diagnosis and intervention.

continued from page 21

depending on their needs and their families' situations."

Finding treatment and qualified personnel who are appropriately trained is challenging. Currently there is a shortage of qualified personnel in all categories. "We are constantly recruiting those who are experienced and trained in ABA," says Pia Durkin, PhD, director of special education for the Boston public schools. "We have great teachers, but finding the therapeutic staff—even aides or assistants—takes time and effort. We are keeping pace at the moment. There is clearly a shortage, but we're lucky; we have been able to meet our need. We are always looking and working on the staffing piece."

Meeting high service demands by providing enough qualified professionals is key to further success in ASD treatment. "One of the most important recommendations in this report was for the federal Office of Special Education Programs (OSEP) to establish a five-year plan. One of our top priorities is funding for the professional development of teachers, paraprofessionals and other personnel for children with ASD," explains Gail Houle, PhD, associate division director of the Research to Practice Division within OSEP.

Families, school systems and experts across the country all worry about the challenge of attracting, training and keeping professionals in this field. "While we are working on many of the recommendations from this report, we are implementing this one immediately and will be working to strengthen this area of our delivery system right away," says Houle.

"Am I doing enough?"

In addition to worrying about the logistics of treatment, parents may be plagued by the stress of keeping their family together. A surge of uncertainty goes through your head frequently when you have a child with complex problems, but you can't help your child if you are overwhelmed. Take a breath. "Realize you can't do it all at once," advises Wiseman. "Parents need help finding balance." The experts suggest setting priorities and focusing on a few items that your child needs now work the best. "Otherwise, you are layering emotional traumas onto an already complex situation for your child and yourself," Wiseman adds.

Staff, time, dollar gaps

Tremendous strides have been made in the past decades for children with autism spectrum disorders. We are diagnosing ASD at younger ages and providing better treatment earlier. From federal and state governments to directors of special education, the capacity to serve these children is growing and strengthening. These improvements give children with ASD a

continued on page 24

One of a kind

There are no formulas at Heartspring, just ongoing dedication to helping children with multiple disabilities achieve their fullest potential. Our multi-disciplinary approach recognizes each child as an individual and provides a plan customized for their specific needs. Your child is one of a kind. Why should their education be anything less?

Heartspring
School

Finding New Ways for Learning

8700 East 29th Street North • Wichita, Kansas 67226
www.heartspring.org

1-800-835-1043

Families in Pennsylvania, New York and New Jersey:

A Heartspring representative will be in your area **April 3-14** to discuss an educational setting unlike any other for your exceptional child. Call today to arrange your appointment.

Circle #19 or visit www.eparent.com/adinfo

> "Studies show that individuals with autism respond well to a highly structured, specialized education program tailored to their individual needs. A well-designed intervention approach may include some elements of communication therapy, social skill development, sensory integration therapy and applied behavior analysis, delivered by trained professionals in a consistent, comprehensive and coordinated manner. The more severe challenges of some children with autism may be best addressed by a structured education and behavior program which contains a one-on-one teacher-to-student ratio or small group environment. However, many other children with autism may be successful in a fully inclusive general education environment with appropriate support."
>
> – *The Autism Society of America*

continued from page 23

better chance to reach their potential.

There are still critical challenges to address, though. They can be summed up in three words: staff, time and dollars. The cost of these programs is enormous, particularly when individualized instruction and treatment are vital. A comprehensive program ranges from 12 to 40 hours per week, including other support services that might be necessary. In a private setting, ABA, for example, can cost more than $40,000 per year. Even in public schools or home-based programs, individual therapies are often recommended for 40 hours per week.

Lord acknowledges that 25 hours of therapy per week is intense for the patient as well as the staff. The benefits of these therapies, however, far outweigh the costs. "Everyone wants the dramatic results that time-intense treatment can achieve," says Lord. "Naturally, parents want what appears to be best for their children." Given that the prevalence of ASD seems to be increasing, and that rise increases the cost of these programs, Lord notes the growing burden for schools, early intervention programs and families, who often must supplement what is offered. "This is a tough situation for all, particularly when families perceive there is only one way to proceed. That is why we have to consider all available treatment alternatives—and be willing to try new techniques as well."

Durkin agrees. "Sometimes in public schools we feel we're in a no-win situation. We offer great programs now, but often these programs are rebuffed by families who have been told they need or should expect something outside the public sector, something different or something more. This may be a result of school systems being less than forthcoming or responsive to families with children with ASD. But in Boston that is changing, and we need to work with families to get them to trust us, try what we offer and tell us how we may need to change."

Given the committee's report, help is on the way. As Lord and Houle attest, these issues have been identified; the concerns have been raised and recommendations made to address them. Lord, Houle and other professionals are now prioritizing the agenda for autism at the federal level. We all await the result of these efforts. EP

Betsy Weaver, EdD, has 20 years of experience working with and for families. Contact Dr. Weaver at: betsyweaver@attbi.com.

Miranda Hersey is a freelance writer and editor specializing in parenting issues; http://www.mirandahersey.com.

With the Creepster Crawler, You Can Watch Your Child Crawl for the First Time!

Children lacking head control, the ability to roll over or belly crawl have gained mobility with the ***Creepster Crawler.*** Using this light, innovative device, hundreds of children around the world are crawling, working more productively with their therapists, and gaining a head start to more advanced mobility in the future.

The ***Creepster Crawler*** is an ideal solution for youngsters with debilitating conditions such as ☐ Spina Bifida ☐ Down Syndrome ☐ Cerebral Palsy ☐ TBI, and ☐ developmental delays. Children with tracheostomies and G-Tubes also are successful users of the ***Creepster Crawler***.

The ***Creepster Crawler***'s frame has a padded platform that can support a parent or therapist from above, making it easier to work with the child on weight-bearing, weight-shifting, reaching and creeping. Front shoulder, chest and rear straps can be adjusted for individual fit.

Call for a Brochure!
1-800-577-1317
Fax: 1-602-242-9211
or email us at info@red-enter.com

RedBarn
ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317** or email us at: info@red-enter.com

CAUTION: Children should not be left unattended in the Creepster Crawler.

Circle #68 or visit www.eparent.com/adinfo

be a **hero** for the tiniest babies

Alex Kingston
of NBC's "ER"

"I know how important it is for babies to get a healthy start, like my daughter did. But today, sadly, 1,232 babies won't be so lucky — because they're born premature. Some are so small they fit in the palm of a hand. Many of these babies will have to struggle just to survive. But the March of Dimes is there helping them win their fight. You can help, too."

Alex Kingston

March
of Dimes®
WalkAmerica®
Saving babies, together®

Join March of Dimes WalkAmerica.
Call 1-800-525-WALK or visit
www.marchofdimes.com/walkamerica
and register today!

Circle #57 or visit www.eparent.com/adinfo

Pedaling with Pete:

One Man's Journey to Raise Awareness About Cerebral Palsy

by Anne Kirkland

In 1989 Pete Zeidner decided he would make a difference. From birth he had battled cerebral palsy to live independently. With the help of two strong and supportive parents and an extraordinary determination and belief in himself, he had succeeded to a remarkable degree. He attended regular schools from seventh grade on and graduated from Kent State University in 1986. But a college education didn't open the doors that Pete hoped it would. Though he went on countless interviews, he always seemed to come up empty-handed. Understandably, he became extremely angry and frustrated and suspected that, due to his disability, no one would give him the opportunity to use what he had learned in college. Then one day he decided enough was enough. He decided to do something with his life and succeed, even if it didn't involve his degree in marketing.

A cycling enthusiast, Pete decided he would raise money for cerebral palsy research by pedaling his custom-built, specially adapted recumbent bike 1,000 miles around the entire perimeter of Ohio. "I believe that anger and frustration are two driving forces in my life, and they can be put to good use in the proper situations," Pete says today. "I was hearing about all of this research being conducted for other conditions like Alzheimer's disease, but I never heard about any research for CP. I decided that was where I could make a difference."

Pete's 28-day ride was so successful at raising awareness—and dollars to fund research—that two years later he started the Pedal

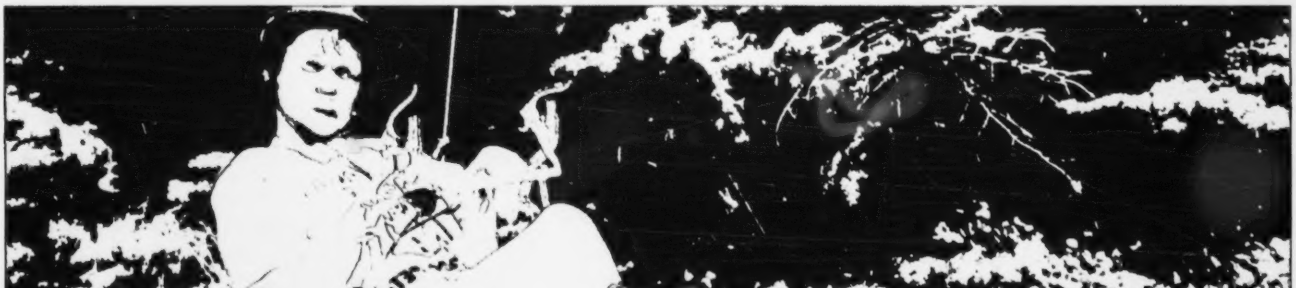


Photo credit: ©Matt Keller/Sage Design Group (http://www.sagedg.com)

with Pete Foundation. Through annual bike-a-thons and other fundraising events, Pete's foundation has to date raised more than $80,000—all for the prevention, treatment and cure of cerebral palsy. No small accomplishment for a first-generation American who has faced more than his share of reversals in his 43 years.

Two Strong Parents

Pete was born in Cleveland in 1958 to parents who immigrated to the US. At first he was not expected to live because of his cerebral palsy. Then, at the age of 4, life dealt him a second cruel blow. His mother was killed in a car accident. When his father Otmar, a physician, remarried, Pete gained a new mother in Haide Zeidner, the person he credits with turning his life around. Refusing to let pity ruin Pete's chances in life, Haide (pronounced HI-dee) chose tough love instead. When Pete was 5, she weaned him off his baby bottle, toilet-trained him and helped him learn to feed and dress himself.

When asked how she had the wisdom not to coddle Pete, Haide answers modestly, crediting her youth and inexperience more than any special insights. It also helped, she says, that, being a stepmother, she didn't experience the guilt that often hampers a biological parent raising a child with disabilities. Instead, she realized that Pete would have to work harder all his life in order to keep up with the rest of the world. Whether or not she made it easy for him now, no one would make it easy for him later.

Today, Pete's praise for Haide is unequivocal. "She accepted me unconditionally as her son, and, although she was very strict with me most of the time, and I hated her for it then, I now realize that she did a great thing for me. I have a lot of inner strength and faith in myself because of Haide's strong belief in tough love."

If Haide was the major influence in his life, Pete also found a strong role model in his father. "As I look back on his life (he passed away in June 2000), I find that he was a very courageous, compassionate and dedicated man. Throughout my father's 81 years, he was the classic example of courage and determination. He loved photography, skiing, hiking and mountain climbing. I especially loved the stories he would tell us about climbing the Alps with my oldest brother, Chris."

With obvious pride, Pete recounts how his father came to the US from Vienna, Austria with a medical degree, a wife and two small children, and worked as an orderly in a New Jersey hospital until he learned English. The year Pete was born, Dr. Zeidner established his own practice in Ohio, the first state that allowed him to take the medical board exam. "What made his practice so successful was his fluency in four languages. He was able to relate to and communicate with a wide percentage of the population."

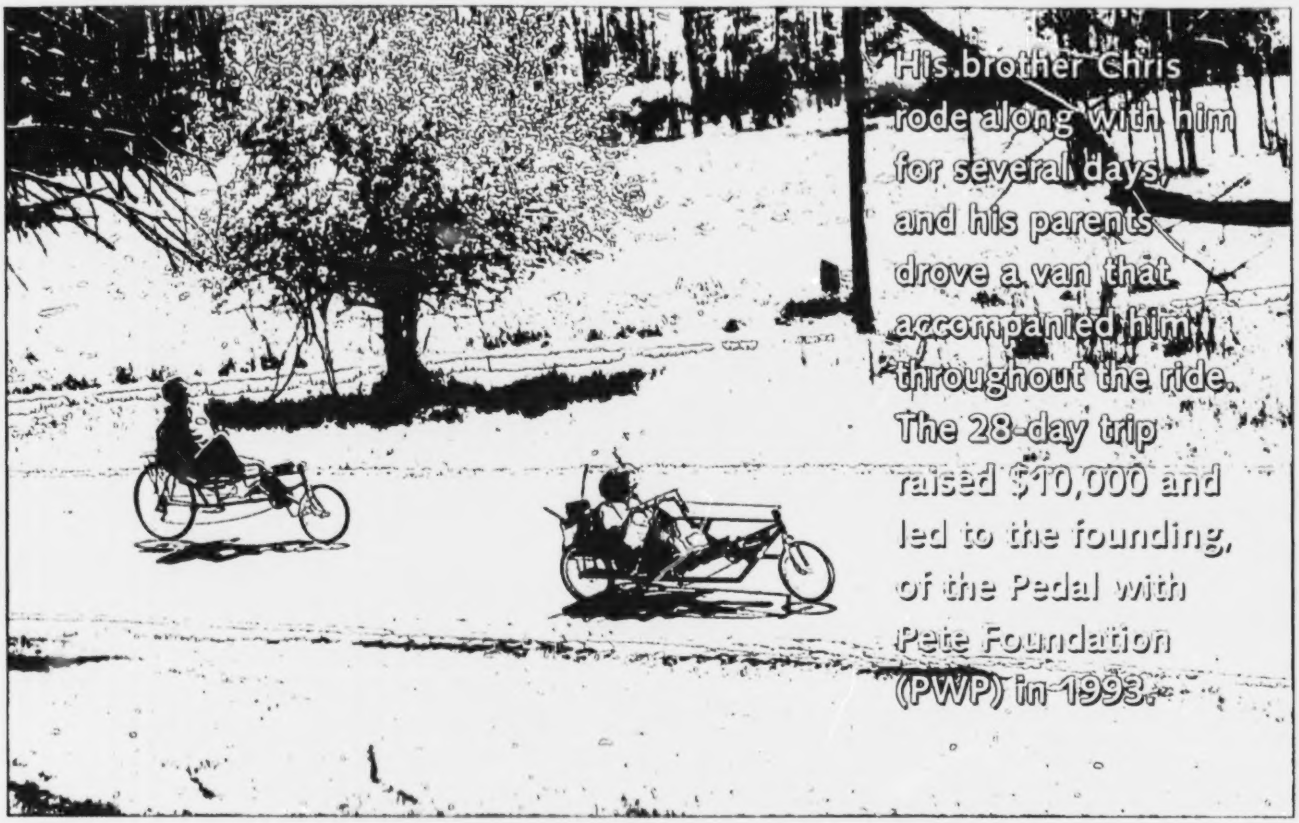
> **Through annual bike-a-thons and other fundraising events, Pete's foundation has to date raised more than $80,000 all for the prevention, treatment and cure of cerebral palsy.**

Though Haide and Otmar didn't always agree on what was best for Pete, they did everything in their power to help him realize his potential. When Pete was in the second grade, they removed him from the special classes he attended at the local elementary school and started him on an intensive exercise program Haide had read about in *Reader's Digest*. The program was based on the philosophy that in order to learn to walk, a child must first learn to crawl. "The program was intended to promote normal development in undamaged areas of the brain and reprogram damaged areas to promote normalcy," Pete explains. "The exercise regimen consisted of crawling and creeping, and swinging on monkey bars."

Some of Pete's most vivid childhood memories involve these grueling workouts. His daily exercises began at 7 AM and lasted 11 or 12 hours, seven days a week. "I was given one or two

continued on page 28

427



His brother Chris rode along with him for several days, and his parents drove a van that accompanied him throughout the ride. The 28-day trip raised $10,000 and led to the founding, of the Pedal with Pete Foundation (PWP) in 1993.

continued from page 27

hours a day for the purpose of home schooling, which I received through an outside tutor," he recalls. Family members also participated in the lengthy exercises, manipulating Pete's head, arms and legs in a series of repetitive motions to simulate normal movement.

Although the American Academy of Pediatrics later issued concerns about the effectiveness of that program, Haide says that for Peter it proved beneficial. She noticed an immediately improvement in his health. Where he had once suffered colds from September to May, he soon became the healthiest member of the family. The rigorous program also had a further benefit. It prepared him to live an independent life.

Proving He Belonged

By seventh grade, Pete could walk well enough to enter a parochial middle school, St. Mark Lutheran School in Cleveland. Though Pete was the only student with a disability in the school, Haide recalls that he was thrilled to be there.

Pete remembers how he made it a positive experience. "In the beginning I felt like I had to prove to them that I deserved to be there and, therefore, I believed that I had to give 200 percent. But it wasn't long before I made many friends. I felt like I fit right in among the other students. I realized that people could look at me and see Peter, not the 'kid with the disability.'"

Along with hard work, he also discovered the value of humor, especially in dealing with embarrassing situations: "If I tripped and fell in the hallway and someone became nervous or upset to see me fall, my friends and I would lighten the situation with a big laugh and say 'I'm just taking a nap,' or 'I thought I saw an M&M down here and I love chocolate.'"

Pete's school experience was so successful that in 1974, Lutheran High School West accepted him on a trial basis. Like most teenagers, he went through a rebellious phase. But he also found his disability to be harder to laugh off than it had been in middle school: "I had a lot of anger and frustration built up inside of me," he recalls. "Although I had many friends that accepted me as I was, I was angry with myself for not being able to do more. I took a lot of my frustration out on my younger siblings, especially when they went out with their friends and I was told I couldn't go along."

Frustrated by his inability to drive or to participate in the new independence his friends enjoyed, he rebelled against the rigors of his exercise program, which, at the insistence of his parents, had continued uninterrupted for ten long years. Stressful times followed as Haide tried to take him in hand. She now believes that the family was too fanatical about the program, saying, "You get hung up on all the things you want for your kids and don't concentrate on enjoying the positive."

So, when Pete turned 18, it was Haide who decided to stop pushing him. With her youngest child, Pete's stepsister, entering first grade, Haide decided to go back to college to pursue a degree in special education. She was not too busy, however, to advise Pete when he was at loose ends after graduating from high school. Although college was not a given for a student with a physical disability, Haide encouraged Pete to take telecourses through the local community college. Later, he attended regular classes at the college and eventually enrolled in Kent State University.

Living on his own at KSU was a big adjustment for Pete. He was very unhappy his first year and wanted to come home every weekend. He might have come home weekends, then never gone back were it not for the fact that Haide once again got tough with him. This time, she had to get tough with the entire family, who believed she was being too hard on Pete. Haide reasoned that if Pete didn't spend at least some of his weekends at school, he would never get used to the social life or learn to make friends. It was a hard battle. "Pete became depressed," she says. "At one point, he even drove his wheelchair down a flight of stairs. He was doing things to sabotage himself. He tried to give up completely but I wouldn't let him. Then, after the first year, he didn't want to come home at all."

True to form, Pete began to make friends and even joined a fraternity. He also got his first computer, which proved to be a lifesaver. It gave him a lot of independence and confidence since he had learned to type back in the second grade, when he used the eraser end of a pencil to punch the keys.

Biking Equals Independence

Pete has always been attracted to tools that augment independence. His attraction to bicycles and the freedom of movement they offered came early. Before he was even out of diapers, he would ride his tricycle around the basement. At 13, to celebrate his church confirmation, his parents gave him an adult-sized trike. "The kind the old folks in Florida ride around on," Pete says with a grin. But because the Zeidners lived in the country, where the highways were busy, Pete was only permitted to ride it in the driveway, so he would simply ride the trike in circles in front of the garage."

It wasn't until Pete was 31 that he got his first heady taste of the freedom biking could offer. His professional business fraternity, Delta Sigma Pi, helped him raise money to buy a custom-built, 36-speed, three-wheel recumbent bike (see sidebar). "I remember riding my recumbent for the first time through the streets of Kent, Ohio, and the ultimate glee that I felt," he recalls. "Maybe it was also the first time that I was able to get up in the morning, take a look at the day outside, and, if the mood struck me, I could get on my bike and go visiting." He would bike to Haide's house or his brother Steffan's—both 60-mile trips each way. Biking gave him the feeling of independence he craved. "I didn't need to rely on others to drive me around and do things when their schedules were free," he remembers. His long years of grueling physical exercises were paying off. "I believe that the exercises toughened me up, not only physically but mentally as well. I became a stronger man because of it."

Pete talks about his recumbent bike

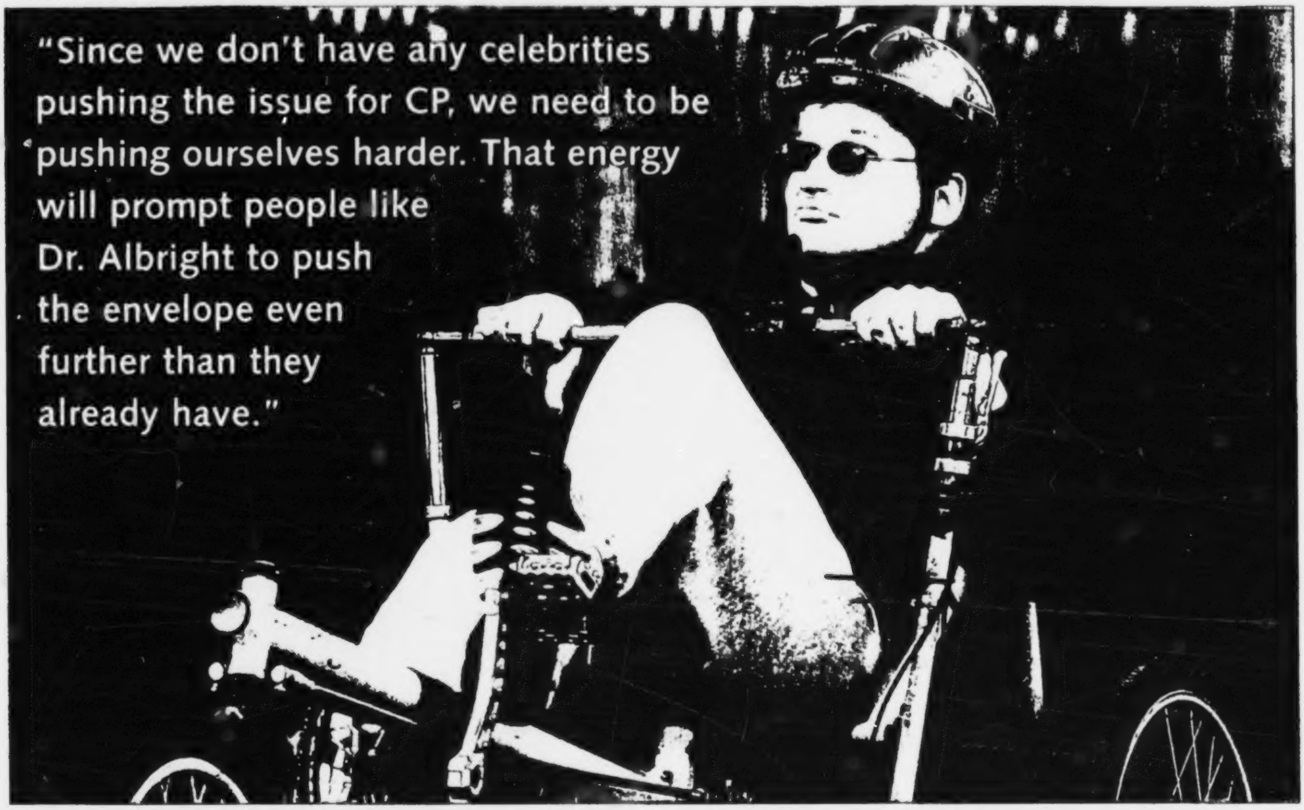
"My first recumbent bike was made by Peach Ridge Pedal Power in Athens, Ohio. The man who made it was a retired engineer who loved to tinker. He built twelve of these recumbents before building mine in a garage behind his house. I needed to have my brother drive me to Athens several times to try out the bike and different adaptations during the course of its construction. For example, the brake handle had to be made larger and run parallel to the handlebars in order to make braking easier for me. Hydraulic brakes were used. The shifters for the gears were longer than is usual and were located close by within my small area of reach. However, shifting was still a great difficulty for me.

"After eight years or so, that bike racked up over 15,000 miles. At that point, it definitely began showing its wear. In the meantime, the salesman of the recumbent had started his own company called Comfort Cycle. He very graciously gave me one of his new bikes, which was two feet shorter that my first eight-foot-long bike. After similar modifications were introduced, the new recumbent was easier for me to get on and off. Since the new bike was also ten pounds lighter, I was able to go faster and travel farther distances. It was also easier to transport. Unfortunately, it was not equipped with a roll bar, which could have made my accident less severe."

During the long hours of blissful pedaling, Pete came up with the idea to ride his new bike throughout Ohio to raise money for CP research. In 1991, Ohio Elks lodges made this dream a reality by helping Pete organize his awesome 1,000-mile statewide bike trip. Family members, who had always been supportive, helped out in planning and completing the trip. His brother Chris rode along with him for several days, and his parents drove a van that accompanied him throughout the ride. The 28-day trip raised $10,000 and lead to the birth of the Pedal with Pete Foundation (PWP) in 1993.

Each May since, Pedal with Pete (PWP) holds its signature Pedal to Make a Difference bike-a-thon event in Kent, Ohio; this year's event is scheduled for May 18. Participants can choose from a 17 or 40-mile bike ride or a two- to four-mile hike. Those who can't participate in the event but still want to support it are

continued on page 30



"Since we don't have any celebrities pushing the issue for CP, we need to be pushing ourselves harder. That energy will prompt people like Dr. Albright to push the envelope even further than they already have."

continued from page 29

encouraged to make donations (with a contribution of $50 or more, donors can be Pete's Pedal Partner, and have their name listed on a poster attached to Pete's bike during the ride.) All proceeds go to support cutting-edge research conducted by Dr. Leland Albright, chief of pediatric neurosurgery at Children's Hospital of Pittsburgh and one of the foremost researchers in cerebral palsy and movement disorders in the world. Some of Dr. Albright's work includes pioneering the use of the intrathecal baclofen pump and deep brain stimulation.

"What I want is a national center for cerebral palsy staffed by people who have a commitment to improving the life of people who have CP, people who are committed to doing research, to studying the different treatments," says Dr. Albright. "I want a center where people can go for state-of-the-art care and evaluation regardless of their problem—whether it is orthopedic, neurological or involves surgery."

Dr. Albright agrees with Pete's assessment that there is very little research being done in CP and lauds Pete's efforts to change that. "He's a remarkable man. He's done more than any single person I know to raise funds for research in cerebral palsy in spite of having severe CP and having had a broken neck and a spinal cord injury. Maybe only someone who has experienced life as an individual with CP really understands how it affects every aspect of every day."

Participation in Pete's bike-a-thons has grown steadily, with more riders and new sponsors joining every year. Over 100 bikers and 30 hikers turned out for last year's event, which generated more than $21,000 for CP research. The annual event has also inspired satellite rides. On August 17, 2002, Pedal with Pete will hold its first bike-a-thon in Columbus. The event is expected to draw more than 300 riders. In Iowa, a 4-H club now sponsors a bike-a-thon in Pedal with Pete's name. The Emmetsberg, Iowa Ride will take place September 2002.

A New Challenge

If Pete's story ended there, it would be a remarkable record of achievement. But life had yet another new challenge in store for him. In 1999, Pete joined 3,000 other riders in the six-day, 50-plus-mile-a-day bike tour known as the Great Ohio Bicycle Adventure. One day, while cycling down a steep hill, Pete swerved to avoid a parked van and landed in a ditch. Eventually tests would show that he had fractured two vertebrae in his neck and sustained a spinal cord injury.

Though he tries to put the accident into perspective, Pete is still angry about his medical treatment after the accident. "I found out that the medical profession doesn't really (care) about cerebral palsy. When I was first admitted to the hospital, they simply sent me home saying there was nothing wrong with me even though I couldn't move a muscle. I was told that I was just in shock over the wreck and that I would be back to normal after 48 hours or so." In fact, he was paralyzed from the neck down.

His recovery was slow and included long months of partial rehabilitation. Yet the most painful blow proved to be the loss of his hard-won independence. Before the accident, he was able to live on his own, with minimal help, in his Kent apartment. Now he requires the almost full-time services of an aide to undertake his once routine daily activities.

Despite the severity of his injury, Pete struggles to maintain his optimism. "My goals are to continue keeping myself strong and fit and keep my sights set on the future, which will be soon I hope, when there will be a cure for spinal cord injuries and an increased awareness of CP." In the meantime, he has found a new role model and source of optimism in actor Christopher Reeve, who sustained a spinal chord injury in 1995. In Pete's estimation, "Reeve has never once taken the low road, made any excuses or given in to discouragement. Instead, Reeve has courageously talked about his injury and daily challenges, and has become the number one advocate for spinal cord research."

Pete hopes to be that kind of advocate for cerebral palsy research. "Since we don't have any celebrities pushing the issue for CP, we need to be pushing ourselves harder. That energy will prompt people like Dr. Albright to push the envelope even further than they already have," he says. Though it is doubtful that Pete will again bike independently (he now rides a tandem recumbent bike with his brother Chris), he holds onto his dream of having the Pedal with Pete Foundation become nationally recognized. "I would like to see Pedal with Pete host bike- and hike-a-thons throughout the country. I would also like to start a Pedal with Pete endowment at the Children's Hospital of Pittsburgh. With an endowment, I believe that Pedal with Pete can achieve greater recognition and reach a new level of participation and sponsorship."

For now, Pete keeps at his daily workouts, which include stretching exercises, sessions using the leg press, lateral pull down and seated rowing machines, as well as cycling on his stationary recumbent bike. Both a physical and occupational therapist assist with these sessions.

Pete says he is also bolstered by his strong faith in God and by the unqualified love and support of his family. "I have a 4-

continued on page 32

THE MELMARK SCHOOL

2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Our approved private day and boarding school serves children ages 5-21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Acquired Brain Injuries
- Cerebral Palsy
- Mental Retardation
- Neurological Disorders

Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

We Offer Your Child:

- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK Ext. 636 or email admissions@melmark.org

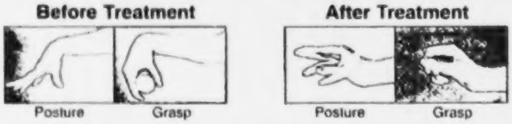
Circle #59 or visit www.eparent.com/adinfo

FIRSTFlex™

improving reach, grasp and pinch together.

Caring For Life

FIRSTFlex™, for children with spastic hemiplegia, combines patented bracing with electrical stimulation.



www.ultraflexsystems.com

Call 1-800-220-6670 for free video and research studies.

Circle #79 or visit www.eparent.com/adinfo

Anchors in different locations when needed.

SUREHANDS®

Gary L., *accountant*, Warwick, NY - Becker's MD

At last, a Lift & Care℠ system as versatile as a pair of hands...and portable, too.

It's a motorized transfer device,
a positioning tool *for posture seating*,
a bathing support,
a hygiene helper *for toileting or diapering*,
a floor space-saver,
a standing support *for some*,
a dressing assistant,
and a back-saver *for carers*.

SUREHANDS LIFT & CARE SYSTEMS

Portable and permanent solutions for homes and workplaces.

1-800-724-5305

e-mail: info@surehands.com • website: www.surehands.com

Circle #75 or visit www.eparent.com/adinfo

continued from page 31

year-old niece, Maddie, and a 2 1/2-year-old nephew, Mateo, who bring such joy to my life. They accept their Uncle Pete unconditionally, and I feel so blessed each time I see them. When I am around them, I briefly forget about having CP and a spinal cord injury." With his many trials, Pete has also received another blessing. "I met a wonderful lady, Chris, about a year ago, and she has brought real joy into my life. I used to dread weekends when others had a significant other to spend their time with. Now I find myself looking forward to the moments that I can share with Chris."

Even with the new hardships he faces as a result of his accident, Pete does not regret the joy and years of independence that biking gave him. In fact, there are still many mornings when he looks out the window, and thinks today would be a great day to go biking. "I loved having the wind in my face," he says, somewhat wistfully, then adds with characteristic humor, "although being so low to the ground did have some major disadvantages, too, (like) that nice, fresh aroma that hovered some warm summer days from roadkill."

Few things have given Pete the sense of completeness and equality that biking gave him. "It was satisfying for me to grind slowly up a very long and steep hill and pass by other bikers who had to get off and walk their bikes up. It was as if I had discovered the place where my inner strength lay. Often times, I would easily pass them on the downhill stretch because of the aerodynamics of my recumbent. At those moments, I would simply smile and wonder what they thought as I smoothly sailed on by."

Despite the hard work, smooth sailing comes easier to Pete Zeidner than self-pity. If there's one message he would like to convey to individuals who struggle daily with cerebral palsy, it's this: "I believe you need to give 200 percent to what you are trying to accomplish. You need to make the extra effort to let people know that you do not feel as if society owes you something because you have a disability. I believe that if you give of yourself, you get a lot more in return." EP

To find out how you can participate in an upcoming bike-a-thon or support cerebral palsy research through the Pedal with Pete Foundation, contact:

Pedal with Pete
P.O. Box 274
Kent, Ohio 44240
1-800-304-PETE
(fax): 330-673-1240,
E-mail: petezeid@aol.com
Web site: www.pedalwithpete.com

Anne Kirkland is a freelance writer who lives in Amesbury, Massachusetts.

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #54 or visit www.eparent.com/adinfo

On the Move

By the Siskin Children's Institute

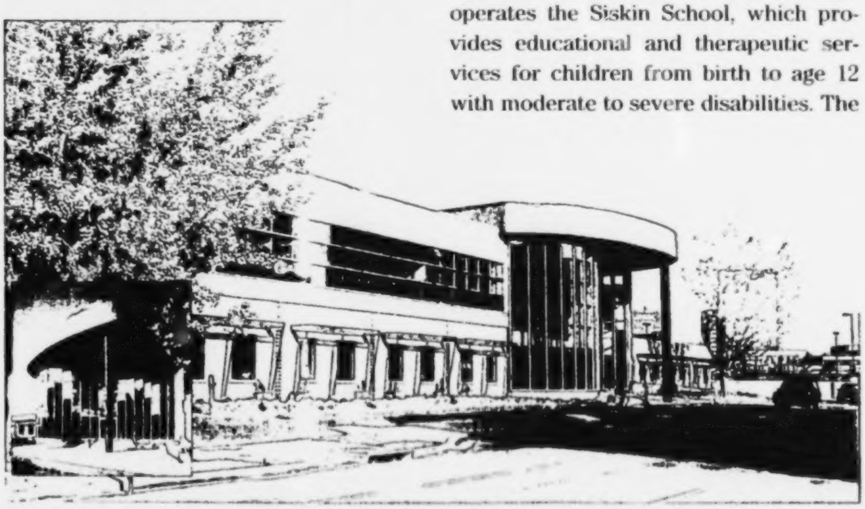
SISKIN
Children's
INSTITUTE

The sound of children's laughter ripples through the new playground at the nonprofit Siskin Children's Institute in Chattanooga, Tennessee. Six-year-old Olivia Helton giggles with delight as she operates a piece of playground equipment from her wheelchair. Grasping a pair of bright yellow handles, Olivia skillfully scoops up sand from the sandbox with a miniature backhoe. A few feet away, several of Olivia's classmates using wheelchairs, tricycles and bicycles glide over the playground's smooth surface. Others play on colorful equipment specifically designed to accommodate children with disabilities, allowing all children to play together.

For children with special needs like Olivia, who has multiple disabilities, the playground at Siskin Children's Institute opens up new worlds of recreational opportunities. Designed by Boundless Playgrounds™ and built by GameTime, the playground provides a fun, safe, universally accessible, developmentally appropriate play area for children of all abilities. "The new playground encourages the physical, emotional, social and intellectual development of our students, and also serves our community as a model of a safe and universally accessible playground," says Paul K. Brock, Jr., president of Siskin Children's Institute.

A model playground is only one of many ways that Siskin Children's Institute is working to meet the needs of children with disabilities and their families in the Chattanooga area. For more than a half century, Siskin Children's Institute has been dedicated to improving the quality of life for these children and their families through excellence in education, support services, advocacy and community partnerships.

"Our broad range of programs and services addresses the challenges of children with special needs—not just educationally, but in all aspects of their development," explains Brock. The Institute operates the Siskin School, which provides educational and therapeutic services for children from birth to age 12 with moderate to severe disabilities. The school offers a full range of services designed to nurture the development of children, including early intervention through family training and classroom programming, school-age classroom programming, the Peer Program, extended care services and comprehensive support services. "The goal of all these services is the same: to help the children reach their full potential," adds Brock.



A New Facility

In August of 2001, the Institute renovated and moved into a spacious 62,000-square-foot building in downtown Chattanooga. The $8.6 million state-of-the-art complex positions the Institute to raise significantly the level of services available for children with special needs and their families and to set a new standard of excellence in the Chattanooga region. In December 2001, a $10 million capital campaign to fund the building and future endowment was successfully completed.

In planning the building, the Institute staff received valuable advice from healthcare and special education professionals. The staff also conducted focus group meetings with Siskin School parents to find out how a new facility could better meet their family's

Supervision is a key factor in safety on playgrounds.

needs. Many features of the new building reflect this input.

Rebuilt from the ground up, the facility includes spacious classrooms, a clinical suite, a children's library and arts center, simulated home environments for family training and a community education center and library. "Our plan was to design a functional and school-like environment in order to provide transitional opportunities for both our families and students. The goal for every child is to transition to natural and less restrictive settings," said Debbie Matthews, Institute director of programs.

A Unique Learning Environment

A colorful land of learning for students lies behind the immense glass walls across the front of the new building. As students and their parents approach the building from the parking lot, the facade of a little red schoolhouse serves as a welcoming point of entry. On the first floor, a large multi-purpose area known as the Commons provides an inviting space for a variety of activities and functions. Offering large views of the outdoors, the area plays host to the children's cafeteria, art projects, indoor play, special events and support group meetings.

Shapes of various size and color guide visitors down the hallways, and brightly painted doors lead into the classrooms. Private observation areas, adjoining each classroom, allow parents to watch activities and identify skills to reinforce at home. Observation areas are also frequently used for training students and professionals in the field of special education and child development. Expanded space in the new building enabled the school to increase the number of classrooms from seven to eleven, increasing capacity from 75 to 115 children.

"In addition to serving children with special needs, the school has an integrated early childhood program for children age 6 weeks to 5 years." At the Siskin School, children with special needs learn alongside children who are typically developing through our Peer Program," says Matthews. "It is the world as it should be —children of all abilities learning together," says Rebecca Caswell, a classroom teacher for children ages 3 to 5.

Learning Activities

Curricular and play-based activities allow children to have fun and learn at the same time. "Each child with special needs has a comprehensive individualized plan, which is a compilation of specific goals and objectives for the year," says Lisa Moore, assistant school director. "Low classroom ratios are maintained and all classrooms are curriculum-based with developmentally appropriate activities. The school not only provides for each child's developmental and educational needs, but also provides a safe and nurturing learning environment for children and families," continues Moore.

Certified teachers and trained assistants facilitate each child's individualized

continud on page 36

continued from page 35

program and encourage parental involvement. "Our staff believes that parent involvement and support are critical to each child's long-term educational success, coping and independence," says Matthews.

Family involvement also encourages parents to exchange ideas and to share information. Parent Patti Frierson frequently discusses medical issues, new medications, and upcoming special education conferences with other parents who have children with special needs. "We benefit from each other's support and experiences," explains Frierson, the mother of a 4-year-old with Down syndrome. "If we have a phenomenal experience with our child, we are able to share that information."

Technology is available to enhance the learning process.

Left: In the therapeutic gym, speech and physical therapists work together to reach goals for each child.

Below: A family participates in the Parent Training Program.

Working Together

A new feature in the complex is a clinical suite with a therapeutic gym. A team of speech/language, physical and occupational therapists, as well as the school psychologist, vision specialist, dietitian and nurses, shares the suite of offices and therapy areas to work together with the children and families in order to meet their individualized needs.

The close proximity of the team promotes frequent collaboration and functional co-treatment sessions in a large, mirrored gym space. For example, during an individual session, the speech/language therapist may work with a child to increase communication and voice production while the occupational therapist addresses positioning and skills that facilitate increased breath support for vocalization. Simultaneously down the hall, the medical director, nurse, dietitian and speech/ language therapist can easily collaborate about a child's oral motor and feeding goals in order to make progress with decreasing tube-feeding dependency while maintaining good nutrition.

Therapy services are also delivered in the child's educational and recreational environments in order to increase functional skills. In the classroom, the physical therapist and teacher may address adaptive equipment so that a nonverbal child can access an augmentative communication device such as a head switch or computer-scanning program. Speech/ language therapists use the playground as a functional therapeutic environment by encouraging turn taking and social language with peers. Physical therapists also utilize the play space to encourage motor skills and increase mobility on a variety of surfaces.

"It takes the entire team working together in order to address the whole child through comprehensive evaluation, programming and direct service provision. Communication with and participation of the family are vital in order for the child to achieve individualized goals and objectives and for skills learned at school to be carried over into the home setting. We know we have done our jobs when a child masters a new skill and generalizes that skill in all environments—home, school and community," says Graham Parker, PhD, school psychologist.

Preparing for Success

Students like 4-year-old Austin Clark, diagnosed with Down syndrome, have greatly improved their communication skills by learning functional sign language at Siskin. Learning sign language has helped facilitate verbal expression and made a tremendous difference for Austin and his family. "The staff has done wonders with Austin," says his mother, Twonna Clark. Austin's father, Tony Clark, agrees: "It's amazing. He is becoming someone who will make positive contributions to society."

Parents with typically developing children in the Peer Program also have access to many resources for evaluating concerns or developmental issues. With low child/teacher ratios, highly trained teachers and access to clinical professionals, Siskin School has become the choice of many Chattanooga families. Heather Ott is the parent of two Siskin students: Parker, a 5-year-old with Down syndrome, and Matthew, a 20-month-old in the Peer Program. Matthew enrolled in Siskin last Fall, while Parker has been a student since he was 2-months-old. "After more than five years of association with Siskin, my husband and I have found that the program does a great job with every child—both typically developing children and those with special needs," says Ott. "Siskin offers an excellent educational program at every level."

Siskin School is the only educational facility in Tennessee that is accredited by the Commission on Accreditation of Rehabilitation Facilities in the areas of Community and Child and Youth Services, which monitors programming for individuals with disabilities by establishing standards of quality. In addition, Siskin School is currently pursuing accreditation by the National Association for the Education of Young Children.

Reaching Out

Community outreach is an important facet of the mission of Siskin Children's Institute. Opening in the spring of 2002, the Institute's Community Education Center will serve as a central resource for families, caregivers, students, educators, medical professionals and other agencies. Emphasizing disability awareness, the Center will provide information and resources regarding special needs, health, safety and recreation. Seminars and workshops will be offered, and parent groups, community organizations and public agencies may request specialized training.

The Community Education Center will have an automated library system with an On-line Public Access Catalog on the Internet. Visitors will be able to stop by

continued on page 38

Special Bikes for Special People

2000

A wide choice of
bikes, colors and
adaptive equipment
for people with
special needs.

Haverich

165 Martell Court, Keene, NH 03431
Tel: 603-358-0438 • Fax: 603-358-0453
www.haverich.com

Circle #47 or visit www.eparent.com/adinfo

The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW

- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made in U.S.A.

Circle #42 or visit www.eparent.com/adinfo

Siskin Children's Institute: The Legacy Continues

Three events—a devastating accident, an urgent prayer and a solemn promise to God—paved the way for the birth of the Siskin Memorial Foundation in Chattanooga, Tennessee, more than a half-century ago.

Badly injured while disembarking from a train in 1942, Chattanooga businessman Garrison Siskin pleaded with God to spare his life. In return, he promised to spend the rest of his days helping those who could not help themselves. God answered Garrison's plea, and Garrison returned home to share the story of his prayer and pledge with his brother, Mose. Overwhelmed by his brother's miraculous story, Mose said, "If it's your promise, it's my promise, and we will keep it together."

To honor their covenant, the Siskin brothers immediately focused their efforts on helping the needy and less fortunate. In 1950, the brothers established the Mose and Garrison Siskin Memorial Foundation as an official step in their vow to help others. Three years later, the Siskin brothers constructed a nondenominational chapel and opened the facility to all races and religions. They soon added an educational building next to the chapel to provide free meeting and office space for charitable, civic, religious, cultural and educational groups in the community.

The brothers also established the Siskin Child Study Center, the first preschool program in Tennessee that provided educational and therapeutic services to children with disabilities, regardless of race, religion or financial status. Today the Siskin School continues the legacy by serving children with moderate to severe disabilities from birth through age 12.

As word spread of the Siskin brothers' generosity, more space was needed to accommodate the increasing number of children and adults with disabilities who sought help and treatment. In late 1959, the Siskin brothers built the $1 million, three-story Siskin Outpatient Rehabilitation Center to serve children and adults, and the brothers spent much of their personal fortunes to finance the project.

Mose and Garrison Siskin dreamed of building a hospital to provide inpatient services for both adults and children. Although they did not live to see their dream fulfilled, their work continued through the Siskin Foundation. In 1990, the Siskin Hospital for Physical Rehabilitation, Tennessee's first freestanding physical rehabilitation hospital, opened its doors to patients. The hospital also provided space for the Siskin School and the Foundation's offices.

Soon after the opening of Siskin Hospital, the Siskin Foundation focused on serving the needs of children with disabilities and their families through the Siskin School. In the late 1990s, the Foundation expanded its efforts to include the safety, health and well being of all children by promoting community and family awareness of child safety.

In August 2001, the Siskin Foundation changed its name to "Siskin Children's Institute" to better reflect its mission of service to children in the community. At the same time, the Institute moved into its new facility in downtown Chattanooga. Today the Siskin Children's Institute continues to uphold the mission of its founders by providing a comprehensive range of programs and services—and by offering a lasting legacy of learning and hope to children with disabilities and their families.

Inclusive classrooms utilize a play-based, language-rich curriculum.

continued from page 37

the Center during normal business hours or explore the collection via the Internet.

Books, pamphlets and reference materials—including information on specific health issues, disabilities, parenting, growth and development, grief and loss, nutrition, safety and recreation—will also be available for checkout from the library. Computer workstations in the Center will provide families and professionals with the opportunity to tap into both local and national resources to supply them with up-to-date information about their disability questions.

Community Initiatives

"To meaningfully increase the level of services available to children with disabilities and their families requires partnerships with other organizations," explained Brock. "Our new building facilitates training with some of our partners." Other collaborations include joining with a local music conservatory, Cadek, to provide Kindermusik in the classrooms.

By providing training for students and

professionals, the Institute can also reach more children and families. University of Tennessee at Chattanooga students in education, nursing, human ecology, physical therapy and occupational therapy receive professional training with the benefits of a hands-on learning lab at the Institute.

Pediatric residents from T. C. Thompson Children's Hospital spend time with Siskin students and staff as part of their behavioral/developmental rotation. Residents meet individually with various staff members to review specific topics, and they are also scheduled to participate in family training sessions, team meetings and classroom programming.

In addition, Siskin hosts training for special education teachers through collaborative in-service training sessions with Hamilton County Schools, the local education agency. Education professionals from surrounding areas also visit Siskin to observe and train on specialized programming issues.

Also, in order to increase recreational opportunities for children with special needs and their families, last summer the Institute, along with four other local agencies, provided a summer camp for children with autism at Chattanooga's Creative Discovery Museum, a children's museum. Plans for expanding this year's summer camp offerings with the museum, the Tennessee Wildlife Center and the downtown YMCA are already well underway. In addition, the Institute is teaming up with the Chattanooga Parks and Recreation Department on the design of the city's next two playgrounds to promote universal accessibility for children of all abilities in the community.

"We are limited in the number of children we can serve within the walls of our new building," says Brock. "By providing training and building these partnerships, we are able to extend our mission to more families in the community and give them choices for their child with special needs. Our goal is to play a vital role in helping Chattanooga become a friendlier place for kids with disabilities and their families." EP

For more information, contact:

Siskin Children's Institute:
1101 Carter Street, Chattanooga, TN 37402
(423) 648-1700 • (423) 648-1749 (fax)
http://www.siskinchildrensinstitute.org

Boundless Playgrounds, Inc.:
One Regency Drive, Bloomfield, CT 06002-2310
(877) 268-6353 • (860) 243-5854 (fax)
http://www.boundlessplaygrounds.org

Exceptional children deserve exceptional care.

The best help for cerebral palsy, spina bifida and related disorders is at Kennedy Krieger Institute.

For 61 years, Kennedy Krieger Institute has been the leader in helping children with severe disabilities. Focusing on early identification, intervention and treatment, our state-of-the-art interdisciplinary team approach—combined with a caring, supportive touch—has enabled generations of children to live their lives to the fullest.

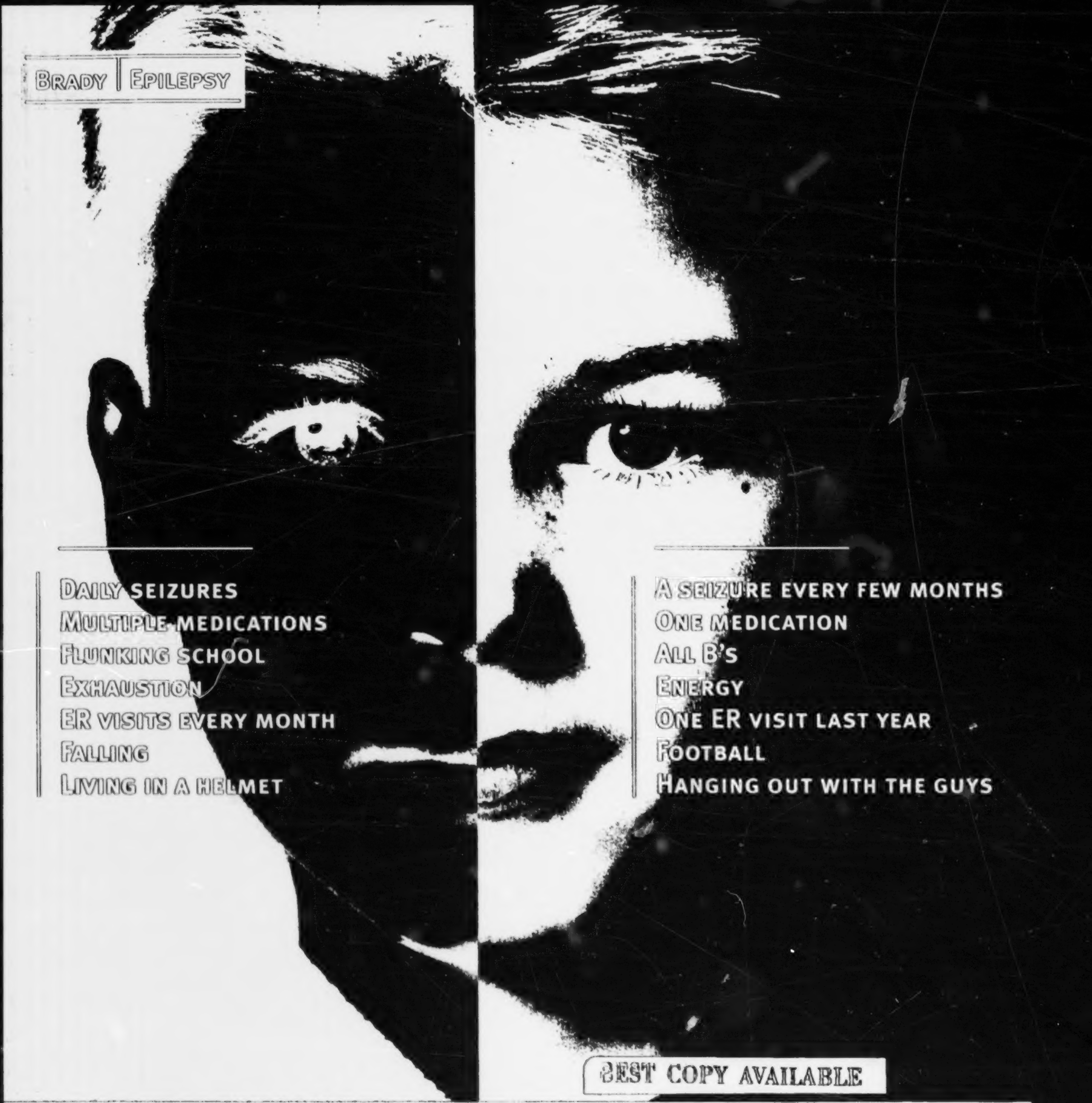
Our comprehensive assessment and treatment for children with cerebral palsy, spina bifida and related disorders includes: Neurology, Medical Services, Nursing, Urology, Orthopedics, Physical Therapy, Occupational Therapy, Orthotist, Clinical Psychology, Neuro-Psychology, Seating, Feeding, as well as Rhizotomy, Spasticity and Movement Disorder clinics.

And unlike many programs, we see patients beyond age 18. Call Kennedy Krieger Institute today. We're here to help.

Kennedy Krieger Institute
707 North Broadway • Baltimore, MD 21205
www.kennedykrieger.org

1-888-554-2080
Kennedy Krieger Institute's Toll-Free Referral Line

Circle #53 or visit www.eparent.com/adinfo


Brady | Epilepsy
Daily seizures
Multiple medications
Flunking school
Exhaustion
ER visits every month
Falling
Living in a helmet
A seizure every few months
One medication
All B's
Energy
One ER visit last year
Football
Hanging out with the guys

BEST COPY AVAILABLE

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

BEST COPY AVAILABLE

NCP
MODEL 101

VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS THERAPY™

VAGUS NERVE STIMULATION

Cyberonics

Circle #30 or visit www.eparent.com/adinfo

A December to Remember

by Frances Ficocelli

Like most married couples, Jim and I were looking forward to starting a family and so were understandably excited when we found out I was pregnant. A few months into my pregnancy, however, complications developed. At one point, I felt unbearable pain and was rushed to the hospital. The doctors told me I had a hormonal imbalance that affected my gallbladder, pancreas, and liver. I was sent home and ordered to follow a low-fat diet and not to gain more than 22 pounds during pregnancy.

As we went on with our daily lives, I tried to find peace. But in my 36th week of pregnancy, I found myself in the emergency room again, this time with a blockage in my intestines. The emergency room doctors decided to deliver the baby immediately via C-section. Within half an hour, Zachary was born. He was a beautiful boy, weighing in at eight pounds, and handsome with his blue eyes and abundant blonde hair.

After Zachary came home, we just enjoyed our lives as he developed into a beautiful, happy little boy. His doctor became concerned, though, when, at 18 months of age, Zachary wasn't talking that much. We decided not to worry, thinking we'll see how things develop by the time he turns 2. When that time came, however, we were very confused and worried about our son. We started noticing his developmental milestones slowing down. He no longer wanted to be held much, and he had very limited eye contact. Worst of all, he wouldn't respond when we called his name. We watched him slipping away.

> Many other parents also complained to the board of education, mostly that the number of children per teacher was high and that another teacher with experience in autism was needed in the classroom.

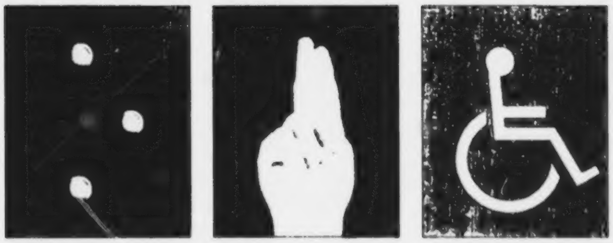
We were really scared. We had no medical insurance at the time because Jim had lost his job. Our doctor told us to call the "Birth to Three" program, and that someone from the program would come out to our home. We called, but it took several weeks for someone to come. For the next few months we didn't know what was wrong with Zachary. The only thing the professionals from the program were able to tell us was that Zachary had "sensory integration problems." At 3, Zachary was placed into the public school system and enrolled in early intervention.

After many developmental tests and observations, the school's psychologist/consultant offered her opinion that Zachary had autism. We were told to read up on everything we could get our hands on and educate ourselves, because we had to act as our child's advocates. For a while we relied on the school to do what was best for Zachary because we didn't know much about autism, or how to teach him. Since I was self-employed, I could be at Zachary's school daily, and I became very involved with his education. Jim was very much involved, too. We worked

continued on page 44

EP selects "parent editorials" for the purpose of providing a forum for emerging opinions and evolving parenting philosophies. EP also welcomes responses to previous editorials that represent divergent views. These select editorials do not necessarily reflect the opinion of EP. — Rick Rader, MD, Editor-in-Chief

Parents may send their submissions for Parent Perspective to Exceptional Parent Magazine, 65 E. Route 4, River Edge, NJ 07661; e-mail: epedit@aol.com. All submissions are subject to review and editing by EP.



Be open. Because some visionaries are blind. Because some communicators are deaf. Because some movers and shakers are paralyzed. Because the only true disability is a mind stuck in the closed position. Be bullish.

ml.com

Ask Merrill

Circle #60 or visit www.eparent.com/adinfo

Adaptivemall.com™

Shop
On-line!

Tim's daughter Carrie.. a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.
Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Jim Carrie !!

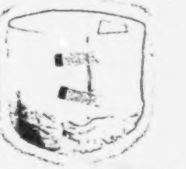
Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #21 or visit www.eparent.com/adinfo

No more waking up wet. Thank you *Woodbury*!

Trial Bag of 10 for $4.99

- Guaranteed to be **the dryest** brief or your **money back**!
- Designed specifically for nighttime use
- **Extra absorbent** core pulls fluid away from skin.



TRANQUILITY.
All Through The Night Disposable Brief

Rated # 1 By Medical Professionals

Call 1-800-431-4242 24 Hrs
Order online: www.woodburyproducts.com

EP502

Circle #83 or visit www.eparent.com/adinfo

continued from page 42

opposite shifts so that Zachary wouldn't be put into daycare. We joined the Autism Society of America and went to workshops and seminars to understand as much as we could about autism.

Zachary had a wonderful second-grade teacher, who unfortunately left at the end of that year. By the time Zachary finished second grade, he was talking a little and was able to answer questions that pertained to his needs. Mostly, he communicated by gestures and body language.

As Zachary got older, neither his ability to communicate nor his academic skills were progressing. Jim and I felt that our son was not getting all the services to which he was entitled. I started calling the State Department of Education to inquire about policies, laws and our rights. I also started researching different teaching methods, as I tried to figure out for myself what was best for Zachary.

When my son reached third grade, he started exhibiting self-injurious behaviors. I'd pick him up at school, and he would have bite marks on his wrists that he had made himself. I would ask the teacher what caused him to do that, and she would tell me "I don't know." I'd ask what was he doing before it happened, she would say "I don't know." So I started coming into the school to observe him and point out for the teacher things that could help to reduce his stress. Things would change for a while, but then the same problems would resurface. He was still hurting himself. This went on for the remainder of the school year. Many other parents also complained to the board of education, mostly that the number of children per teacher was high and that another teacher who had experience in autism was needed in the classroom.

At the end of the school year, when we met with the planning and placement team (PPT), Jim and I informed the school that we felt the program was not working for Zachary. They disagreed and said that he was making good progress. I told them that I wanted him out of the self-contained classroom and placed in a mainstream setting. I was concerned that the classroom environment might be causing his self-abusive behaviors since the classroom was small, the noise level high, and there were a number of disruptions from the other children with autism. In addition, the aides in the classroom were not properly trained.

Jim and I decided to wait for Zachary's four-month report to see just how much progress he had made. These reports had our 9-year-old son at the developmental level of a 4- to 5-year-old. The people from the program thought that was great. Then they told me, you really couldn't go by the tests; they don't give a true score.

Jim and I decided we had to do something to help our son. I was worried about his years in middle school. I knew he wouldn't have a chance in a regular classroom because he would be so far behind his peers, and I didn't want him to be kept in a self-contained classroom. I wanted him to get an education beyond learning functional and vocational skills.

So we started by informing the school that we wanted a program in place to help Zachary be mainstreamed. The school officials told us that he could not be mainstreamed until he stopped his non-purposeful language. So for his fourth grade IEP (individual educational plan), we put in for his goals and objectives a program to reduce his non-purposeful language. We hoped that ultimately when he reached middle school, he would be mainstreamed for part of the day and in a resource room for the rest. In the resource room he could work on his goals individually, and in the regular classroom he would benefit by being with peers.

When the fall came and Zachary entered fourth grade, we were asked to wait until he settled into his routine before the program was implemented. After a month, his medication was changed for medical reasons, and again they asked us to wait until Zachary got adjusted to his new medication. By January of that school year, they said they "were still taking data." Jim and I played their game for a few more months until we decided to hire our own psychologist.

When I informed the school that I had hired a psychologist, they scheduled an appointment with me to discuss the program they wanted to implement. At the meeting, they explained the procedure: they wanted to give him stickers every time he did not use non-purposeful language–as many as 200 a day. I expressed my concerns, indicating that stickers would not be an appropriate reinforcer; it was like giving him a sticker every 2 minutes! They asked me to let them try it for two weeks and see what happened. I asked what they would do in two weeks if it didn't work. They said, "We haven't thought that far ahead yet."

Four school days later, I picked Zachary up at school, and I almost fainted. My little boy was covered with pinch marks across his entire chest and down both arms. I asked his teacher what had happened. She told me he did this to himself. I marched him into the nurse's office and told her I wanted this

continued on page 46

HYPERBARIC OXYGEN THERAPY

Brain Injuries ~ Cerebral Palsy ~ Near Drowning ~ Stroke ~ MS ~ Lyme Disease

- ☑ Combined 30+ years experience in the hyperbaric field.
- ☑ Care-giver accompanies patient in MULTI-place chambers.
- ☑ NEW chambers with AIR CONDITIONING, entertainment systems and comfortable seating.
- ☑ Experienced Medical Directors are MD's.
- ☑ Facilities are open 7 days/week.
- ☑ Friendly staff makes the experience personal, comfortable, and pleasant.

Two state-of-the-art facilities for your convenience:

Northeast U.S. & Canada

TORONTO HYPERBARIC INC.
Mississauga, Ontario, CANADA
Phone: 905-306-0770
Email: help@torontohyperbaric.com
www.torontohyperbaric.com

Southern U.S.

HyperTec
Olney, Texas, USA
Toll Free: 1-800-218-3588
Email: bbailey@hypertec.ws
www.hyperbaric-health.com

EP neither endorses nor denies the effectiveness of this therapy. For our Editor-in-chief statement see our Contents page.

Circle #78 or visit www.eparent.com/adinfo

Connetquot West, Inc.
Health Care Products

Mobility • Bathroom Safety • Specialty Seating
Beds/Patient Rooms/Lifts • Nutritional/Enteral
Respiratory • Diabetic Supplies • Ambulatory

Home Delivery!

Providing the Nation with Top Quality Service & Healthcare Products at Competitive Prices

Incontinence/Underpads • Urological • Skin Care
Pressure Management • Wound Care • Personal Care
Diagnostics • Exam/Treatment • Protective Apparel

For more information, please call
Toll-Free: 866-588-3888
Fax: 866-588-3337
Email: connetquot@aol.com
711-3 Koehler Avenue • Ronkonkoma
New York • 11779

Circle #27 or visit www.eparent.com/adinfo

DRIVE-MASTER

50 YEARS of Providing Mobility for the Physically Challenged

STEERING YOU IN THE RIGHT DIRECTION

Innovators Then...

Partial Features Include...
- Hand Controls
- Reduced Effort Steering
- Reduced Effort Braking
- Foot Steering
- Left Foot Gas Pedals
- Wheelchair Lifts
- Porch Lifts
- Steering Devices
- Backup Brakes & Steering
- Horizontal Steering
- Complete Van Conversions
- Block Pedal Extensions

And Much More!
For additional info. contact Drive-Master

Experts NOW!

DRIVE MASTER

9 Spielman Road, Fairfield, NJ 07004-3403
Phone: (973) 808-9709 • Fax: (973) 808-9713
E-mail: drivemaster@drivemaster.net
Web: www.drivemaster.net

24 HOUR TURNAROUND SERVICE

Circle #32 or visit www.eparent.com/adinfo

continued from page 46

documented, as we knew he had not gone to school in this condition. We also took pictures and made an appointment to see his doctor.

Jim and I went through hell and back over the next few months. We had to prove Zachary was not getting the education that was right for him. We asked for an emergency PPT meeting, and I made phone calls to find an advocate. Jim and I realized we could no longer handle this ourselves. We called L.D.A. (Learning Disabilities Association). We rejected the school's program and asked for an independent evaluation (outside the school district). Then we had to take ALL the necessary steps to prove that the program was no longer appropriate for Zachary's individual needs. And we did it!

Zachary is now attending a private school that specializes in his individual needs. This year we had the best Christmas ever. We got to see our son have a part in a school play for the very first time. The play was called "Santa's Got Mail." And every one of the children participated, their parts decided by their abilities. Because Zachary's communications skills are weak, his part was to perform dance steps to music, and he was coached to do so. All the children did a wonderful job. I commend the staff at his new school. They treat the children with respect, and the children's accomplishments reflect the staff members' efforts. I thank God every day that he is there.

It's been several months since the two incidents of self-abusive behavior—the biting and pinching that caused Zachary to regress—occurred. Since then, he has not been able to talk in a normal voice. He only feels safe when talking in a whisper. We pray every day that this is only a short setback, that in time he will regain the confidence to communicate the way he used to.

Jim and I firmly believe that God gives us only what He knows we can handle. Even though we may ask "why" or question "What did we do to deserve this?" only God knows His plan for us. We were created to do God's work; He has a special mission for all of us. Some people may never know what the purpose of their life is. I am proud to say that I know what mine is: to love and care for Zachary to the best of my ability, to teach him and help him to be as independent as God wants him to be. God's children have a place in our world, regardless of abilities or disabilities. Zachary continues to teach us that every day.

In the short time Zachary has been at his new school, he has grown in independence and self-confidence and, most important, he is learning to trust again. EP

Frances and James Ficocelli have been married for twelve years. They and their son Zachary live in Connecticut.

AN INTRODUCTION TO:

Early Childhood Sensory Integration

Carolyn O. Cantu, MS, OTR

> *"He avoids playing with other children." said the preschool teacher. "Sometimes I think he may be shy, headstrong or just not feeling well. He also refuses to play at the activity centers."*

The parent/teacher consultation was taking place after hours in the child care center. The play behaviors of 3 year-old Jamie worried the preschool teacher. His parents and a pediatric occupational therapist (OT) listened while Jamie merely watched his twin sister dart in and out from under the center's toy parachute. Jamie's behavior raised concerns: watching other children play, overtly refusing to participate, avoiding tactile play substances such as sand, clay or finger paint, and pulling away from touch or hugs were becoming daily occurrences. He seemed to tolerate physical contact only when he himself initiated it. If taken by surprise by the touch of another child or teacher, he cringed, ran away and cried. Snack and lunch times were becoming stressful for Jamie and the staff. He refused to eat most food sent from home, selecting only crunchy or tart items.

The parents contributed their home observations. They were becoming frustrated with their son's refusal to dress in the morning, his screaming while washing his hair or face, and his pulling at his clothes. At night, he refused to sleep under the covers. Jamie rejected most foods at meals, preferring such crunchy food as French fries, onion rings, and potato chips; occasionally he would try fried chicken. His pediatrician was concerned about his recent weight loss, and his overall health concerned his parents.

Identifying the Problem: Understanding Sensory Integration

What was happening? Jamie's twin sister did not display any of these behaviors. Was Jamie competing for attention? Why did he avoid daily activities his peers seemed to enjoy so much? Did other children show these behaviors? Most important, how could Jamie be helped? Could he, too, explore and learn through his environment while feeling safe and secure?

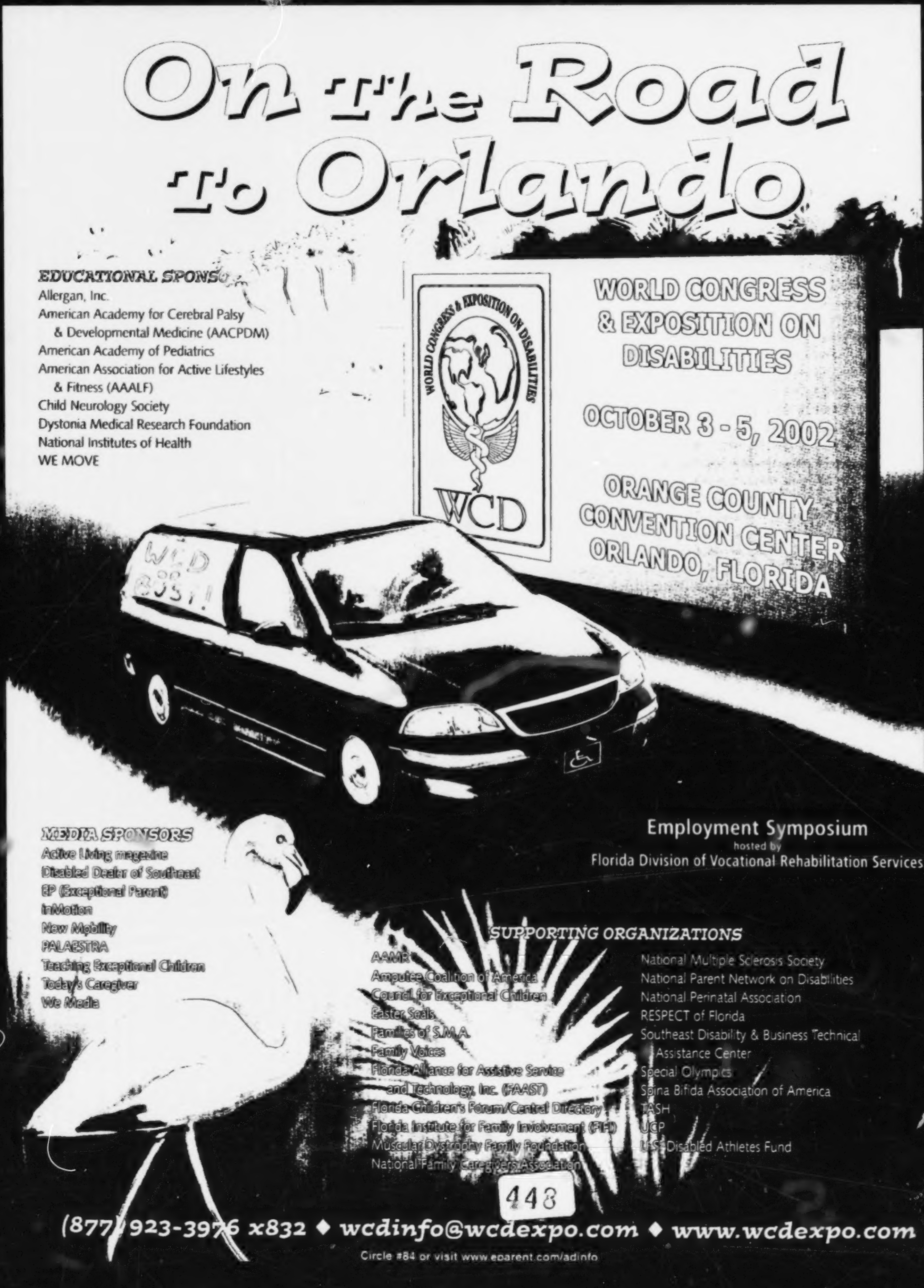
> *Children with sensory problems often are either at high alert (hyperreactive) or unresponsive (hyporeactive) to their environment*

The answers to these questions lie in the explanation of the possible cause of these behaviors. Such symptoms, independent of any other medical cause, may indicate problems with sensory processing, known to physical therapists (PTs) and OTs as **sensory integrative dysfunction.** Disorders in sensory functioning can greatly influence a young child's ability to interact with peers and experience the world.

Thirty years ago, A. Jean Ayres, PhD, OTR, a neurophysiologist and occupational therapist, identified this neurological integration process. Dr. Ayres attempted to explain the relationship between sensory motor behaviors and neural functioning, and suggested that there exists a strong correlation between neural function and the child's degree of success in academic learning. In her book, *Sensory Integration and the Child*, Dr. Ayres explained that normal sensory integration is the organization of sensory information applied to everyday activity. In a child's case, that everyday activity is play. As early childhood teachers know, learning is directly related to the exploration of the environment through play experiences. Sensations of activity enter the child's brain, are

continued on page 52

On The Road To Orlando


WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD
WCD or BUST!

WORLD CONGRESS & EXPOSITION ON DISABILITIES

OCTOBER 3 - 5, 2002

ORANGE COUNTY CONVENTION CENTER ORLANDO, FLORIDA

EDUCATIONAL SPONS

Allergan, Inc.
American Academy for Cerebral Palsy
& Developmental Medicine (AACPDM)
American Academy of Pediatrics
American Association for Active Lifestyles
& Fitness (AAALF)
Child Neurology Society
Dystonia Medical Research Foundation
National Institutes of Health
WE MOVE

MEDIA SPONSORS

Active Living magazine
Disabled Dealer of Southeast
EP (Exceptional Parent)
InMotion
New Mobility
PALAESTRA
Teaching Exceptional Children
Today's Caregiver
We Media

Employment Symposium
hosted by
Florida Division of Vocational Rehabilitation Services

SUPPORTING ORGANIZATIONS

AAMR
Amputee Coalition of America
Council for Exceptional Children
Easter Seals
Families of S.M.A.
Family Voices
Florida Alliance for Assistive Service
and Technology, Inc. (FAAST)
Florida Children's Forum/Central Directory
Florida Institute for Family Involvement (FIFI)
Muscular Dystrophy Family Foundation
National Family Caregivers Association
National Multiple Sclerosis Society
National Parent Network on Disabilities
National Perinatal Association
RESPECT of Florida
Southeast Disability & Business Technical
Assistance Center
Special Olympics
Spina Bifida Association of America
TASH
UCP
U.S. Disabled Athletes Fund

(877) 923-3976 x832 ◆ wcdinfo@wcdexpo.com ◆ www.wcdexpo.com

Circle #84 or visit www.eparent.com/adinfo

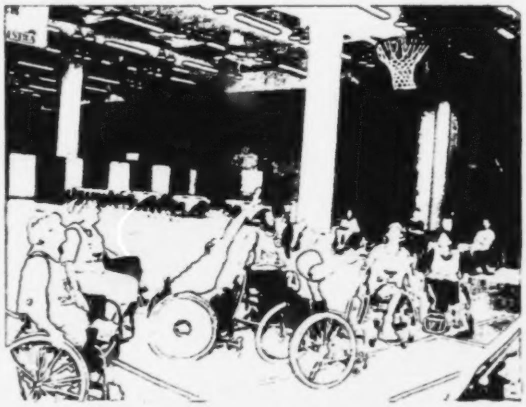
Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—October 3 - 5, 2002
LOCATION:
Orange County Convention Center—Orlando, Florida

A UNIQUE GATHERING—A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract **physicians ○ families ○ direct support professionals ○ people with disabilities ○ allied health care professionals ○ educators ○ adapted physical education specialists.**



TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.

SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more.

EMPLOYMENT SYMPOSIUM PAVILION: Human resource managers will discuss career opportunities.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.

CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment.

- All WCD attendees can experience discussions by internationally renowned experts specializing in neurology, orthopedics, pediatrics, internal medicine, family medicine, physical medicine, epidemiology, DDS, movement disorders, mitochondrial and metabolic disorders, neonatology, seizure disorders, autism, and other disabilities and chronic conditions as well as general practitioners.
- CME and CEU accreditation will be provided through approved accreditation institutions.
- Hear parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.
- An Employment Symposium produced in conjunction with the Florida Department of Education, Division of Vocational Rehabilitation Services will offer sessions for people with disabilities, their families and employers.
- Learn from special education professionals what is going on in classroom environments.
- Participate in adapted physical education activities and seminars.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

SHOW PRODUCER: HAB H.A. BRUNO, LLC **IN ASSOCIATION WITH:** EP Exceptional Parent **GOLD SPONSOR:** sigma-tau PHARMACEUTICALS, INC. **CONFERENCE SPONSOR:** EP Foundation for Education, Inc.

EDUCATIONAL FORUM TO HIGHLIGHT...

THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

The third annual World Congress & Exposition on Disabilities (WCD), produced by H.A. Bruno, LLC, will once again present an incredible conference program by offering over 150 educational sessions. The uniqueness of this program is the multidisciplinary focus. Each session is designed to educate many disciplines within the disability community. During the intensive three-day educational experience, information and ideas on today's most important issues will be exchanged between people with disabilities, their families and caregivers and opinion leaders in medicine, science, education, research, technology, and product development. The conference will take place October 3-5 at the Orange County Convention Center in Orlando, Florida.

"Attending the WCD is like going back to college," exclaimed Amanda McIntire, Inclusion Coordinator for Child Care Resource Network, Daytona Beach. "I acquired so much knowledge, interacted with a diverse population, and had a difficult time choosing which 'classes' to take."

The conference program is sponsored by the EP Foundation for Education, Inc., a 501(C) 3 not-for-profit organization, with the assistance of EP Exceptional Parent Magazine and supported by the National Institutes of Health, the Child Neurology Society, WE MOVE and other professional societies and organizations. From pediatrics to geriatrics, some of the seminars will address seizures and seizure management, mitochondrial disorders, spasticity, Project DOCC, learning disabilities, universal newborn screening, movement disorders, perinatal health care, autism and PDD, reimbursement, pain management, the Medical Home, orphan drugs and dental care.

An adapted physical activity program, sponsored by PALAESTRA Magazine, will offer sessions on physical fitness programming; motor skills and gross motor activities; aquatics; APE around the world; various sports such as scuba diving, golf, skiing, goalball, etc.; inclusive indoor and outdoor activities; and much, much more.

"It was refreshing to see parents, doctors, therapists, classroom teachers and adapted physical educators all grouped together with a common interest," said R.R. Apache, Assistant Professor at the University of Nevada.

In addition, the WCD conference program is collaborating on a 50 session employment symposium with the Florida Department of Education, Division of Vocational Rehabilitation Services (VRS) and other statewide provider/advocacy organizations. The purpose of this event is to provide individuals with disabilities, employment counselors, and various employers, with a forum for information exchange. The Employment Symposium will additionally provide participants, individuals with disabilities, Vocational Rehabilitation Services staff, employers, and others with an opportunity to engage in various employment focused discussion sessions.

Continuing Medical Education (CME) accreditation for designated seminars will be offered. Continuing Education Units (CEU) accreditation will be awarded for OT's, PT's, speech and language pathologists, recreational therapists, and social workers through local chapters of national associations. CEU accreditation for educators will be awarded by the Council for Exceptional Children.

In addition to the education forum, WCD will also feature an employment pavilion sponsored by VRS and McDonald's Corp. and a sports & recreation activity center. Attendees will also have an opportunity to examine the latest products and services from more than 250 exhibitors representing pharmaceutical, assistive technology, automotive, mobility, durable medical equipment, personal care, computer, insurance, nutrition, and many other industries.

Virtual WCD

www.vwcdexpo.com

☒ View the latest products and services
☒ Read updated news items
☐ Communicate with people in the disability community
☐ Use the comprehensive bulletin board

EXHIBITORS

- A.C.F. Environmental
- AAMR
- Acorn Stairlifts Inc.
- Active Living Magazine
- Advanced Respiratory
- Advantage Vans of Central Florida
- Allergan, Inc.
- American Academy for Cerebral Palsy & Developmental Medicine (AACPDM)
- American Association for Active Lifestyles & Fitness (AAALF)
- Amputee Coalition of America
- Anew International
- Angelman Syndrome Foundation
- Anne Carlsen Center for Children
- Aquatic Access Inc.
- Aurora Ministries
- Best Bath Systems
- Beyond Adversity TV
- Bodypoint Designs Inc.
- Body Sense
- Cambrooke Foods
- Canine Companions for Independence
- Challenge Publications
- Child Neurology Society
- Cloister Creek
- Communication Access Network
- Concord
- Convaid Inc.
- Council for Exceptional Children
- Crotched Mountain
- David Mandt & Associates
- DBH Attachments Inc.
- Defense Threat Reduction Agency
- Department of Veterans Affairs
- Department of Defense Dependents Schools
- Dietary Specialties
- Disabled Dealer Magazine
- Dolphin Human Therapy
- Downi Creations Inc.
- Driving Aids Development Corp.
- Dystonia Medical Research Foundation
- Easter Seals
- Economic Mobility
- El Dorado
- EP (Exceptional Parent)
- EP Foundation for Education, Inc.
- Families of S.M.A.
- Family Voices
- Federal Medicare Agency
- Flaghouse Inc.
- Florida ADA Leadership Network
- Florida Alliance for Assistive Service and Technology, Inc. (FAAST)
- Florida Children's Forum/Central Directory
- Florida Independent Living Council
- Florida Institute for Family Involvement (FIFI)
- Ford Mobility Motoring Program
- Freedom Concepts
- Gabby's
- Guldmann Inc.
- Heartspring School
- Hewlett Packard
- Hoveround Corp.
- inMotion Magazine
- Invacare
- International Broadcasting Bureau
- Island Dolphin care, Inc.
- JayJo Books
- KayJae Manufacturing Co., Inc.
- Learning Strategies, Inc.
- Magitek.com, LLC
- McDonald's Corporation
- Merrill Lynch & Co., Inc.
- Muscular Dystrophy Family Foundation
- MyMedMart, Inc.
- National Disability Sports Alliance
- National Family Caregivers Association
- National Institutes of Health
- National Multiple Sclerosis Society
- National Parent Network on Disabilities
- National Perinatal Association
- Newhope Generation
- New Mobility Magazine
- Oxy-Health Corporation
- PALAESTRA
- Pathways Development Group, Inc.
- Perkin Elmer Life Sciences
- Possibilities Foundation, Inc.
- Pride Mobility Products Corp.
- RESPECT of Florida
- Ricon
- Rifton Equipment
- Sammons Preston
- Scooter Lift Mfg Co.
- Search Beyond Adventures
- Shire US Inc.
- SHS NORTH AMERICA
- Sigma Tau Pharmaceuticals, Inc.
- Social Security Administration Office of Disability
- SourceAbility
- Southeast Disability and Business Technical Assistance Center
- Southpaw Enterprises, Inc.
- Special Olympics
- Spina Bifida Association of America
- Sunrise Medical
- Super Duper Publications
- SureHands Lift & Care Systems
- TASH
- Teaching Exceptional Children
- The Autism Recovery Foundation
- The Center for Discovery
- The Disability Resource
- The Liberty Motor Co.
- Theradapt
- Today's Caregiver Magazine
- UCP (United Cerebral Palsy)
- U.S. Department of Justice
- U.S. Disabled Athletes Fund
- Vail Products, Inc.
- Vision For Life
- WALMART
- We Media
- WE MOVE
- Wheelchair Getaways

Exhibitors at press time

Please send me information on the World Congress & Exposition on Disabilities, October 3-5, 2002

I AM INTERESTED IN: ☐ Exhibiting at the Show ☐ Attending the Show

Name

Company

Address

City State Zip Code

Telephone Fax

Email

Send Me Information:
877-923-3976, x832
Fax this page to:
201-226-1236
Mail this page back to:
WCD
210 Route 4 East
Suite 403
Paramus, NJ 07652
Email your request from:
www.wcdexpo.com

For complete details, visit our website at www.wcdexpo.com, or call: (877) 923-3976 ◦ (201) 226-1446

Early Childhood Sensory Integration

continued from page 47

matched with information already stored there, and are processed to make an effective response. If these sensations are not processed in an organized way, the child will have the kind of outsize reactions Jamie exemplifies.

In everyone's sensory processing system, the brain first receives and organizes information through the senses, then it integrates the new input with information already in the system. If the sensations are disorganized they do not integrate well, as ultimately reflected in behaviors. Information is naturally received through the five senses: sight, hearing, smell, touch and taste. The brain also receives sensory information from additional sources: the **tactile** or touch sense; the sense of joints' position in space, **proprioception;** and the ability to interpret movement in relation to the earth's surface (upright, upside down, lying sideways), the **vestibular** sense. Sensory motor skills are then built upon these basic senses. They include the ability to integrate both sides of the body in bilateral coordinated movement, as in riding a bike or in playing a musical instrument, and motor planning, which is the natural ability to execute movement or sequences of movements without thinking about them. This last skill is based on a strong sense of proprioception. Most self-care activities—dressing, for example, brushing teeth, other grooming—fall into this category.

Children with sensory problems often are either at high alert hyperreactive or unresponsive (hyporeactive) to their environment, because they lack the sensory integration needed to attend to an activity without being distracted by outside stimuli. Think of a child listening to a story who becomes distracted by the airplane flying overhead.

Self-regulation is the last area considered in the scope of sensory integration disorders. Children with self-regulation problems usually demonstrate unusual sleeping patterns, eating difficulties and self-calming issues.

Children with difficulty sensing where their bodies are in space are often described as clumsy or "a bull in a china shop."

Red Flags of Sensory Integration Dysfunction

- Increased sensitivity:
  to sights bright lights, sounds, movements
- Decreased sensitivity:
  craves touch, has high pain tolerance, prefers spicy foods, throws self against people or walls
- Marked increase or decrease in activity level:
  perpetual motion, tires easily, increased sleep
- Coordination problems:
  walking delays, problems with climbing, balance, trips/falls frequently, difficulty with cutting or drawing
- Speech or language delays
- Attention and self regulatory problems:
  distracted from activity by background noise or extra visual stimuli, appears on edge, is difficult to soothe

Evaluation and Intervention

Jamie's behaviors indicate disorganization in the tactile system. His central nervous system is being overloaded with tactile messages because his brain is not organizing that sensory information. He demonstrates a clear hypersensitivity to touch, generally called **tactile defensiveness.** This causes behavioral consequences that are demonstrated two ways: protection from tactile overload by squirming, pulling away, running away, and crying; or shutting down completely by refusing to participate or pushing food away. These are Jamie's defense mechanisms when his brain fails to integrate effectively.

Other children may exhibit different unexplained behaviors. Children with difficulty sensing where their bodies are in space are often described as clumsy or "a bull in a china shop." They may not be able to move smoothly from one part of a room to another. Often a child cries and remains frozen in one spot, unable to plan movements to the next location. These patterns of behavior are what Dr. Ayres described as **sensory integration dysfunction.**

Is it possible for this neural disorganization to be addressed? Is it possible for solutions to be presented at home and in school that will enable integration of sensory information? The answer to both questions is yes. After identifying which of the processes are causing problems, a pediatric OT or PT can select appropriate activities for the child. These activities will either increase tolerance for particular stimuli or decrease the craving for them. Activities are designed, ordered and sequenced to desensitize tactile overreactions, regulate movement (e.g., excessive jumping and spinning), integrate both sides of the body, increase proprioceptive input, and increase the ability to plan sequential movement.

Activities are selected from these categories depending on the needs of the child:

- Auditory;
- Visual;
- Olfactory (smell);
- Gustatory (taste);
- Tactile tolerance;
- Vestibular maturity;
- Body scheme and bilateral integration;
- Attention and self-regulation;
- Proprioception, position in space and motor planning

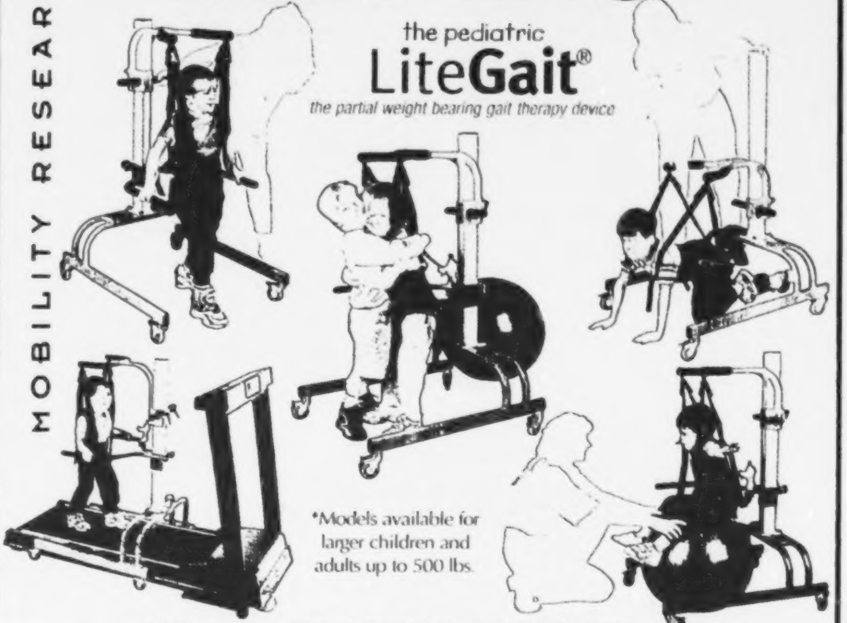
A child may exhibit symptoms in one or more of these categories. It is up to the OT to identify the areas of delay or dysfunction and to work with parents, teachers and others on the child's team to develop an effective treatment plan.

Therapists may be consulted through an Early Childhood Intervention (ECI) program or through a private practice listing. Although some therapists have extra certification in the theory, evaluation and treatment of sensory integration disorders, there are many licensed therapists who are trained and experienced in this specialty without having the extra certification. In some states, such as Texas, doctor's orders are not necessary for a therapy evaluation and consultation. Physician's orders for the therapist to commence treatment, however, are generally required.

Parents and teachers are usually the first to observe sensory processing difficulties. After discussing their concerns, the first and most important step is a thorough pediatric examination to determine whether a medical or neurological problem might be the cause for the child's behaviors. At this point, either the pediatrician or the teacher

continued on page 54

Up & Walking...*and so much more*
with WalkAble™
MOBILITY RESEARCH
the pediatric LiteGait®
the partial weight bearing gait therapy device



*Models available for larger children and adults up to 500 lbs.
LiteGait.com ▪ MoRe@LiteGait.com ▪ 480-829-1727
800-332-WALK WalkAble.com
Circle #61 or visit www.eparent.com/adinfo

HDIS
Convenient Home Delivery of Bladder Control Products

Find the right brief for your child in our Sample Pack!

$5.99 Sample Pack

Not sure which brief is best for your child? Then give 5 of the best known brands a try for just $5.99. Our Youth Brief Sample Pack includes one each of the following briefs:

- Attends®
- Tranquility®
- Tranquility® All-Through-the-Night
- TENA®
- Wings® Choice Plus

Call now for a FREE sample!
1-800-2MY-HOME®
(1-800-269-4663)

"We're here to help... and to make your life easier."
- Mary

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

©2002, HDIS 024-128

Circle #44 or visit www.eparent.com/adinfo

Early Childhood Sensory Integration

continued from page 58

may refer the child to an OT or PT for a sensory integration assessment.

By using parent/teacher interviews, clinical observation, and the administration of formal and standardized tests, the therapist determines the cause and extent of these sensory behaviors. The results are then presented to the parents, physician and teachers and a cooperative treatment plan is drawn up. This plan usually includes an ordered progression of sensory and sensory-motor activities. Consultation with the parents and teachers includes reinforcement for activities in the home and school environments, encouraging a collaborative effort toward treatment and success. Progress reports are to be presented to parents, teachers and physicians on a regular schedule.

After all the observations, interviews and evaluations are complete, the OT may conclude that Jamie exhibits a definite pattern of tactile defensiveness. Therapeutic intervention involves a desensitization program to address this condition. Using a therapeutic "brushing" technique (where a brush is gently run over arms and legs) as demonstrated and monitored by the therapist, Jamie would receive desensitization input enabling him to tolerate touch and tactile substances. Various craft activities might follow, focused on desensitizing his aversion to textures. Activity suggestions for home and the classroom may include tactile experiences such as moving from coloring with markers, to using chalk, to finger painting. The therapist has many varied gross and fine sensory motor activities to use with the child and suggest to parents and teachers. **EP**

Carolyn O. Cantu, MS, OTR, is a licensed pediatric occupational therapist and educator with thirty-two years of experience who has practiced and taught all over the world. Most recently she was a pediatric therapist and clinical educator for the Infant Parent Program, Austin, Texas.

For more information on sensory integration in children log onto www.nmark.com/si/ or www.tsbvi.edu/Outreach/seehear/fall97/sensory.htm.

Suggested sensory motor activities for preschoolers:

Tactile desensitization

- Hidden Treasures—bury small objects, such as mini dinosaur toys, in rice or beans;
- Dry materials bins, sand table—fill with a selection of oatmeal, flour, rice, barley, other grains;
- Shaving cream projects;
- Gardening and indoor plants—digging holes, planting, repotting;
- Pudding paint projects;
- Baking/baking projects—making pizza dough, grating cheese; rolling out and cutting cookies, putting them on cookie sheets.

Proprioception/position in space/motor planning

- Pushing, pulling or lifting against joints, ligaments and tendons, leading to sequential components of a task.
- Hopscotch, jumping, skipping, mini trampoline (feet, knees, bottom);
- Jumping over string tied between two chairs;
- Simon Says;
- Marching (lifting feet high and stamping to musical rhythms);
- Animal walks (bear crawl, elephant walk, bunny hopping, frog hop, crab walk;
- On playground—jungle gym, kickball, volley ball, modified tug of war, riding tricycles.

Vestibular activities

- Rocking horse;
- Balance beams;
- Rocker boards;
- Incline games (climbing up/down on feet, back or stomach);
- Tunnel crawling;
- On playground—jungle gym, moving play ladders, rolling on flat ground or small hills, climbing tires, swings, scooter boards.

Motor planning activities

- Tunnels;
- Mazes;
- Floor maps to be used with toy cars;
- Obstacle course;
- Play cones set in pattern to parade through.

Olfactory/gustatory activities

- Identification with eyes covered of common fruits and vegetables;
- Prepared kits are available for developing discrimination of these senses.

Marked improvement of sensory integration difficulties is often celebrated after a child's participation in a sensory integration program. With occupational or physical therapy sessions reinforced by home and school programs, Jamie and other children with similar sensory integration disorders may begin to experience their world joyfully and without stress.

BEST COPY AVAILABLE

Book and Resource List for Parents

Anderson, Elizabeth and Emmons, Pauline. *Unlocking the Mysteries of Sensory Dysfunction*. Available from www.amazon.com, Children's Special Needs Books.

Ayres, A. Jean. *Sensory Integration and the Child*. Los Angeles: Western Psychological Services (WPS). 1994. Contact WPS 12031 Wilshire Blvd, Los Angeles, CA 90025-1252; (310) 478-2061; fax (310) 478-7838; web site http://www.wpspublish.com.

Koomar, Jane. Making Sense of Sensory Integration. Audio cassette and booklet available from http://www.amazon.com, Children's Special Needs Books.

Kranowitz, Carol Stock. *The Out of Sync Child*. Skylight Press Paperback 1996. Available from http://www.amazon.com, Children's Special Needs books.

Reisman, Judith. *From Roots to Wings*. Sensory Processing Video for Parents at imaginart@compuserve.com or the American Occupational Therapy Association's online store, http://www.store.aota.org.

Williamson, G. Gordon and Anzalone, Marie E. *Sensory Integration and Self Regulation in Infants and Toddlers*. National Center for Infants and Toddlers. Contact the Center through their Web site, http://www.zerotothree.org.

Sensory Integration International
1602 Cabrillo Avenue
Torrance, CA 90501
(310) 320-9986
Web site: http://home.earthlink.net/~sensoryint

Accessibility without renovation! Eliminate bathroom transfers!

Go from commode to shower and never transfer!

Roll into position next to the tub and inter-lock to the tub frame slide rails.

Entire seat slides over the tub.

Enjoy your shower!

Shocked at the HIGH cost of a Ôroll-inÕ shower renovation... you need the ÒSLIDERÓ!

The SLIDER, bathing system eliminates costly Ôroll-inÕ shower renovations, bathroom transfers and other family members donÕt lose access to a bathtub. The SLIDER works with any standard built-in tub and rolls directly over any commode. Easy access pull out foot rest, adjustable tension back support, push handle, seat belt and open front, padded commode seat for easy access to the perineal area are standard. The SLIDER utilizes 5Ó total lock casters and has two swing-away arm rests for lateral transfers. Sliding seat functions in either direction. Pediatric, Narrow and Extra-Wide models available. The SLIDER bathing system... a **cost effective** alternative to bathroom renovation. SLIDER dimensions: Between arms- 17.5", Overall width- 21", Seat depth- 18" Seat height - 24", Weight capacity: 250 lbs, Ships: UPS. Reclining ÒTilt-In-SpaceÓ model available. Master Card & VISA accepted.

Assistive Technology Inc. *530 S. Whittaker St. #240, New Buffalo, MI 49117*
Ph: 800 478-2363, 219 522-7201, Fax: 219 293-0202 E-Mail: info@pvcdme.com Web: www.pvcdme.com

Circle #20 or visit www.eparent.com/ad info

A PARENT'S GUIDE
A step-by-step approach

Written by the founder of the first college prep high school for kids with NLD and Asperger's Syndrome, this compassionate guide helps parents learn essential skills they need to help their child overcome and cope with the symptoms of these often debilitating disorders

Helping a Child with Nonverbal Learning Disorder or Asperger's Syndrome

by Kathryn Stewart, Ph.D.
www.orionacademy.org

A new book from New Harbinger Publications

ISBN 1-57224-277-9 $14.95
(800) 748-6273 www.newharbinger.com
High-quality self-help books that teach essential life skills

Circle #62 or visit www.eparent.com/adinfo

LIVING & LEARNING

STUDENTS AT THE EVERGREEN CENTER learn to live in the community and reach their full potential. Our Basic Skills and Behavior Development Centers, community residence programs and supportive staff combine to create a caring environment allowing students to achieve a greater degree of personal independence.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631
Serving students with developmental, medical and behavioral needs since 1981.

Circle #36 or visit www.eparent.com/adinfo

NATIONAL HUMAN GENOME RESEARCH INSTITUTE AND THE NATIONAL INSTITUTES OF HEALTH OFFICE OF RARE DISEASES Launch New Genetic and Rare Diseases Information Center

Submitted by The Genetic and Rare Diseases Information Center

The National Human Genome Research Institute (NHGRI) and the National Institutes of Health's Office of Rare Diseases (ORD) have launched a new information center that delivers free and immediate access to information specialists who can provide accurate, reliable information about genetic and rare diseases to patients and their families, health care professionals and biomedical researchers.

There are more than 6,000 genetic and rare diseases afflicting more than 25 million Americans, but many of these illnesses affect relatively few individuals. As a result, information about these rare disorders may be limited or difficult to find. The new service, called the Genetic and Rare Diseases Information Center, will help relieve this problem by providing reliable information about individual disorders. Opened in February 2002, the center provides experienced information specialists who can personally answer questions from patients and family members via text (TTY) and traditional phone, as well as by e-mail, fax and mail.

"I am delighted we can provide a resource that should be of great benefit to individuals with genetic and rare diseases and their families," says Francis Collins, MD, PhD, director of NHGRI. "Valid and accessible information about these conditions is hard to find, and having an information center staffed by professionals will provide a critically important service. The National Human Genome Research Institute is delighted to be partnering with the Office of Rare Diseases to establish this center."

ORD Director Stephen C. Groft, PharmD, who currently is on detail as executive director of the White House Commission on Complementary and Alternative Medicine Policy, knew there was a need for a genetic and rare diseases information center when he was executive director of the Commission on Orphan Diseases. "It was a dream of his way back in the 80s," said Henrietta Hyatt-Knorr, ORD's acting director. "The commission heard over and over again from people with rare diseases: 'We need information.' Now people can talk to someone—personally—and get information right away." Hyatt-Knorr continues, "There will be a quick turn around, too. If you just received a diagnosis for yourself, your spouse, or your child, now you won't have to wait to find useful information."

The center operates under a contract with Aspen Systems, an information management company that creates and manages information systems for many health and government agencies. Aspen Systems oversees the technology supporting the NHGRI/ORD information center. The Genetic Alliance, an international coalition of more than 300 lay advocacy organizations and health professionals, staffs the center with information specialists supported by sophisticated technology and the latest information.

"This new Genetic and Rare Diseases Information Center will be staffed by specialists sensitive to the needs of individuals and families with genetic and rare diseases," says Mary Davidson, executive director of The Genetic Alliance. "The experience of reaching a live, compassionate person with accurate information can be lifesaving to many people."

The center provides callers with authoritative information about specific illnesses from existing public-domain sources, including reliable Web sites, brochures, articles and even chapters from books. Experts at the information center ensure that the material sent out is current and accurate. The center, however, does not provide genetic counseling and does not offer diagnostic testing, referrals, medical treatment or advice.

The information center expects most inquiries to come in by phone or e-mail. Calls are answered Monday through Friday, from 12 noon to 6 p.m. Eastern Time by phone and TTY (text telephone). Inquiries submitted via e-mail, fax or US mail will receive a written response from an information specialist within five to ten business days. **EP**

THE GENETIC AND RARE DISEASES
INFORMATION CENTER
P.O. Box 8126
Gaithersburg, MD 20898-8126
Telephone: Monday - Friday,
12 noon to 6 PM ET
(888) 205-2311 • (888)205-3223 (TTY)
Fax and e-mail: 24 hours per day
(202) 966-5689 (Fax)
E-mail: gardinfo@nih.gov

Mail will be answered within five to ten business days upon receipt. 24-hour e-mail or fax will be answered within five to ten business days.

Contact information for the Center is also available on the NHGRI and ORD Web sites:

NHGRI Web site:
www.nhgri.nih.gov/Info_center
ORD Web site:
rarediseases.info.nih.gov/info_center

Office of Rare Diseases

National Institutes of Health

THE CENTER FOR CHILDREN • HOSPITAL FOR JOINT DISEASES

Caring for children with
Cerebral Palsy
requires the help of many specialists.

Now you can find them all at
one special place.

The Center for Children is the one place you'll find all the care options you need, with just one concern in mind: your child. By bringing together the resources of the Hospital for Joint Diseases (HJD) and the Rusk Institute of Rehabilitation Medicine (RIRM) of NYU Hospitals Center, we can care for a variety of conditions in one convenient setting. For example, you'll find the widest possible range of treatments for children with cerebral palsy, with in-house specialties including pediatric physiatry, orthopaedics, speech therapy, neurology, neurosurgery, physical and occupational therapy. All in a gentle, kid-friendly environment where there are no white coats, but plenty of color, interaction, toys, games and stimulation. From newborns to 21-year-olds, The Center for Children treats them better. **Call us at 212-598-2330.**

The Center for Children
Hospital for Joint Diseases
301 East 17th Street • New York, NY 10003 • www.jointdiseases.com

For additional comprehensive pediatric services, contact:
NYU Medical Center
NYU Children's Health
866-CHILD-NYU

MOUNT SINAI NYU HEALTH

Circle #77 or visit www.eparent.com/adinfo

ADVERTISEMENT

Universal Newborn Screening

In 1961, Dr. Robert Guthrie of the University of Buffalo developed a laboratory test to detect phenylketonuria (PKU) in newborns. PKU is an inherited metabolic disorder resulting from an enzyme deficiency; if left untreated, it results in profound mental retardation. In 1963 Massachusetts became the first state to mandate screening for PKU, which can be treated by lifelong dietary management and counseling. The National Association for Retarded Children (now The ARC), the Children's Bureau and the Kennedy Foundation were foremost among the organizations that pushed for widespread adoption of the Guthrie test, and by 1966 it was required for all children by all 50 states and the District of Columbia.

Dr. Guthrie and other researchers continued to develop newborn screening (NBS) tests to detect many more disorders, and each state decided what screens would be available for its newborns. Significant disparities resulted; in 1997, in Massachusetts, infants were tested for 10 or more disorders, while Utah's babies were screened for three. Montana and South Dakota each mandated three tests and offered one other by special request only. In the same period, with the introduction of ever-smaller and more powerful microprocessors, technology and equipment became significantly more sophisticated. This permitted testing that had not been feasible before. A process called tandem mass spectrometry (tandem MS, MS/MS) can now run tests for nearly 40 disorders at one time. None are curable, but all are treatable.

In the last two years, many states have expanded their NBS programs. Almost all Pennsylvania hospitals now offer the full spectrum of testing, although the law mandates testing for only six. Massachusetts routinely screens for more than 15 disorders and is running a pilot program offering 30+ tests. Wisconsin has almost tripled availability, from 7 tests to 20. Yet universal NBS still engenders much controversy, and there are many issues to be resolved before consensus can be reached on how the US will move forward.

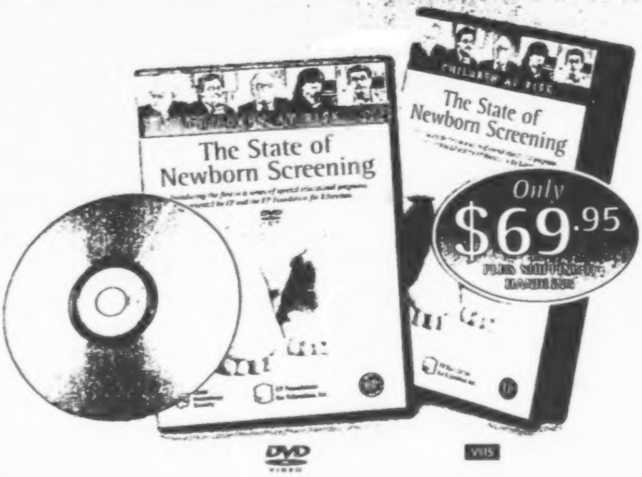
The data tells us that of the four million babies born in the US each year, ten to twelve thousand may have one or more of these detectable...and treatable...disorders

ISSUES: These may be economic, political, professional, sociocultural, religious. Capital spending, training, payment policies, long-term follow-up; insufficient hard financial data; union issues; professional knowledge levels and practice habits; citizen knowledge, and cultural and religious beliefs and practices; insurance, managed care companies, Medicaid, ChIP programs, the uninsured—all these and many more must be part of discussions and resolution.

With the current system, a child born in Louisiana with galactosemia will likely live a life marked by mental retardation and other special health care needs, while similarly affected children born the same day in most of the rest of the country will receive immediate treatment and become productive members of society. The data tell us that of the four million babies born in the US each year, ten to twelve thousand will have one or more of these detectable disorders, an almost-negligible number. The overall cost or benefit to our society, though, will vary wildly from one child to another because of the patchwork of screening availability. We as a nation must find a way to embrace universal NBS and make it routine for all children born in the US. More than that, it is downright wrong not to do so when it has proven its worth time and again!

It is a question of education and awareness. Research shows that the average couple planning to have children does not know anything about existing screening programs, much less the capabilities offered by tandem MS, largely because OB/GYNs, pediatricians, genetic counselors and related professionals are not familiar with universal NBS. The education gap relates to professionals and consumers, rich and poor, people of every race, religion and ethnicity. Few people know much about any of the issues. Worse, among the people who do profess knowledge of NBS and the issues, a good deal of what they "know" is wrong.

The information you need on Newborn Screening is finally available on DVD and video



Children at Risk:
The State of Newborn Screening

is now available on DVD and VHS. Introducing the first in a series of special educational programs presented by EP and the EP Foundation for Education, Inc., a 501(C)3 Not For Profit Corporation.

EP Foundation for Education, Inc. Child Neurology Society EP

Newborn screening can detect up to 39 metabolic disorders from one blood spot. All are treatable when diagnosed at birth, offering the chance for a full and productive life.

Leading medical and scientific professionals are gathered to provide the most current information available. You can view this valuable resource at your convenience and the DVD is indexed so that key topics are easily accessible.

Darryl DeVivo, MD
SIDNEY CARTER PROFESSOR OF NEUROLOGY
COLUMBIA UNIVERSITY

Piero Rinaldo, MD, Ph.D.
DIRECTOR, BIOCHEMICAL GENETICS LABORATORY
MAYO CLINIC

Edwin Naylor, Ph.D.
PRESIDENT
NEOGEN SCREENING, INC.

Joan E. Pellegrino, MD
ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES
UMDNJ: ROBERT WOOD JOHNSON MEDICAL SCHOOL

Paul M. Fernhoff, MD
MEDICAL DIRECTOR
EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA MasterCard CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #50 or visit www.eparent.com/adinfo

Who am I?

It was Free Play time. As always, the children had many choices: books, theme-related toys, sensory materials and gross motor activities. Naryan came into the classroom and successfully put his belongings away with the assistance of an adult and a picture skill sequence (a pictorial step-by-step guide to the activity). He found a book, sat down and examined each page closely. When he finished the book he went back to the first page and began again. The adult with him suggested that he move on to another activity. When Naryan did not respond, the adult tried to help him put down the book and move on to something else. Naryan grabbed for the book, flung his head back and arched his body. He protested loudly, then ran from the adult. His behavior was difficult and could be considered non-compliant. Why did he behave this way?

PROFILE
A Self-Statement from your child's perspective

Corinne G. Catalano, MA,
Purnima Rathi Hernandez, DDS, MA,
Patty Wolters, COTA

A CHILD WHOSE DEVELOPMENT IS DELAYED may be unable to communicate his feelings to others accurately. When he tries to express his feelings, his attempts may be perceived as odd, inappropriate, even inexplicable. Consequently, both the child and the adults in his life become frustrated.

Each child has a unique personality shaped by temperament, relationships and her rate of maturation in other developmental domains, including expressive and receptive communication, cognition, sensory integration and motor planning, and gross and fine motor skills. With an enhanced understanding of the child's development, we can begin to think about why she is or is not doing something or how she might feel when not engaged. When we imagine experiencing the world as if we were that child, we gather information that can be very helpful in understanding feelings and behaviors.

Writing a "self-statement" or profile from the child's perspective

The goal of this article is to offer broad guidelines for the organization of the thoughts and observations used to create a profile. Included are a sample profile written by a parent, the therapists' reactions to it and a list of uses for a profile compiled from actual experiences.

Suggestions in organizing your thoughts and writing a profile

The profile seems to be most effective and meaningful when written in the first person. For many years, specialists in the field of child development have used this technique in their work. Writing the profile in the first person allows us to experience life from the child's perspective, and helps us to gain a clearer picture of the interrelated development of the child's affective, social, communicative, motor and sensory experiences.

Naryan and his mother Purnima work on sensory integration with Corinne Catalano from the Demonstration Program.

It is imperative that the child be represented as accurately as possible.

Close interactions and observations are key in writing the document. Each and every interaction we have with the child has meaning and is an opportunity to learn something about the child and ourselves. We must become the expert in knowing the child's likes and dislikes in order to represent them well. We need to spend time watching the child from a distance as he goes through daily routines and spend time engaging with him.

continued on page 62

Sample of a profile

This is a sample of a profile presented in the form of a letter written to Naryan's new speech therapists prior to his first visit. The intent of the letter was to introduce the child and help the therapists prepare for the session appropriately.

August 30, 2001

Dear Michelle and Estelle,

Thank you for calling and asking about me. My mother is enclosing my extensive medical history. Also enclosed is a photo of me so you know that I am one handsome dude.

Here are a few additional things about me.

- My balance is poor and I am a very active boy. So most of my energies are expended trying to get my gross motor under control. But when I sit down I can finally concentrate on other things. Sometimes my mother has to force me to sit.
- I love music of any kind. My favorites are nursery rhymes, Barney songs, Mozart and rock especially Queen. Music regulates me and my mother uses it to teach me many skills.

I love to read books and I learn well from books, videos and other visuals. My mother says I am visually impaired, whatever that means, so I need to see things up close and at an angle. I will let you know by my actions when I need to get closer. I am now pointing to each word in the book. In fact I can recognize many words.

- My mother uses numbers, alphabets and colors while teaching me language since I know them well. It usually gets my attention better.
- I usually will take you to what I want and can use at least five picture communication symbols. I don't like signing anymore, but if I find something motivating then I will do anything for it. In fact today I indicated lollipop for the first time. My mother was so happy that she gave it to me in the living room, which usually is not allowed.
- I love using the computer and am very good with mouse skills.
- I have an odd look about me but I understand more than I show. At most times I have a hard time expressing. They say I have apraxia.
- I DO NOT LIKE MY MOUTH TOUCHED. I guard that with all I have. But this summer I have worked hard on allowing more things near and in my mouth so that you both could get near me. I WANT TO TALK. I have so much to say. My first words were Amen and Mama. I can now say others like: caaaa (car), ice cream man, computer, but only my mother can understand them. I say "oh! Mam (man)" is used clearly and purposefully.

I come with many diagnoses pervasive developmental delay, visual impairment, and reflux but I really am a cute, innocent, happy and loving guy. I am looking forward to meeting you both and starting a happy lasting relationship.

Sincerely,
Naryan Hernandez

Response of the therapists to the profile

The profile told us that this parent was very involved in every aspect of the child's life. Also that this parent had a thorough understanding of the child's need. The medical history document and the profile gave a clear picture of the child's medical conditions, behavioral patterns, likes and dislikes and weaknesses. The profile document helped us to prepare appropriate stimulating materials for the first meeting. The parental description also allowed us to determine the physical parameters needed. The profile of this particular child delineated visual deficits, so material could be appropriately positioned from the start of the visit. Since verbal communication was not the child's primary means of communication, alternative augmentative systems could be put in place immediately. Since the parent advised that the child was orally defensive, the therapist did not bombard the child with PROMPT™ (a hands-on type of therapy).

The profile gave an accurate and precise description of the child and we were pleasantly surprised at actually how the first session went.

—Estelle Solomon, MS, CCC/SLP and Michelle Solomon MS, CCC/S

For Family Freedom
Get a Superarm Lift

Handicaps, Inc.

- Quick installation
- Doesn't Block Door
- 3 Year waranty
  5 year limited
- Less Cost
- V.A. tested
- Load in seconds
- Less Parking Space

"We are absolutely delighted with the Superarm Lift. The major advantage is the ease and unobtrusiveness with which it mounts to the van. It is so much more attractive than the various elevator contraptions. The lift has increased our son's mobility by 100%. We enthusiastically recommend the Superarm Lift."
Mr & Mrs Crowl - Tulsa, OK

- Fits full-size vans, RV's & some mini-vans *(ask us)*
- Lifts Electric & Manual chairs *tell us if you have seat inserts*

Visa and MasterCard accepted
Call or write for a free brochure

4335 So. Santa Fe Dr.,
Englewood, CO 80110
Fax. (303) 761-6811

1-800-782-4335
www.handicapsinc.com

Circle #45 or visit www.eparent.com/adinfo

Camphill Special School
Children's Village

A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- Pennsylvania Approved Private School
- Waldorf Curriculum (Member of AWSNA)
- Both Day & Residential Programs Available

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236
www.BeaverRun.org

Circle #24 or visit www.eparent.com/adinfo

Writing a Profile:
Sample of questions to ask under each developmental domain

Expressive and Receptive Communication:

1. Do I communicate with others and how? (i.e., gestures, words, phrases, augmentative systems)
2. Is it difficult for me to understand things people tell me to do or questions they ask me?
3. What helps me to understand? (i.e., visual cues, fewer words, time to process what they said)
4. How do I feel when I can't communicate my needs and ideas? (i.e., angry, frustrated)
5. What do I do when I can't communicate? (i.e., scream, hit, withdraw)

Cognition:

1. Can I look for something I was playing with after it goes out of sight?
2. Can I represent my feelings and ideas with my words and gestures or through my play?
3. Can I use past experiences to solve my problem? (i.e., drag a chair over to reach something out of reach)

continued from page 60

It is often helpful to note and then analyze our most pleasurable and most difficult times with the child, focusing on three very important variables: the environment, the child and ourselves. For example, many parents find that the child's evening bath provides a very pleasurable time for all of them. The quiet room, warm water and familiar toys may create a calming environment for the child. The feel of the water against his body may help him adjust, and he is happy and more accessible to others. He might be able to carry out the ideas he has for what to do with the bucket and the boats filling the tub. He may also relish the slow-paced, one-on-one time with his parent. The parent can wind down after a busy day, and enjoy the child's bath-time activity.

On the other hand, many parents report that large family gatherings are very difficult for their children. The environment is usually loud, busy and crowded. The parents are probably anxious and may be feeling that all eyes are on their child who is acting difficult and is not interacting with other children. The child is being bombarded by stimuli including voices and faces that are unfamiliar. The other children are moving and talking at a pace that is too fast for him. Unable to handle this environment the child begins to scream and cry or retreats into the safe haven of his own world.

By observing the child in different situations and environments, and working with other therapists and educators, we will learn more about the child's strengths and weaknesses in each of these developmental areas. As we put ourselves in the child's place by writing his self-statement or profile, we will

continued on page 64

Sensory Integration and Motor Planning:

1. How does my body feel most of the time? (i.e., floppy and tired, overexcited and uncomfortable)
2. What helps my body calm down or wake up so I can tune into the world and other people? (i.e., burying myself in pillows or beanbags, jumping, marching, swinging, running)
3. Do I know where my body is in space? If not, what kinds of things do I do to help me understand where my body is? (i.e., lay on the floor so that I can feel each part of my body, sit in a chair with arms so I can feel where I am)
4. Can I organize and feel the stimuli that come at me though my different senses? Do I get overwhelmed because I can't shut out unimportant stimuli? Do I close my eyes or cover my ears so that I only have to pay attention to one type of stimulus? (i.e., auditory or visual)
5. Do I have ideas about what I want to do? (i.e., build with blocks, climb the ladder, play with toy cars) Do I know how to start? Do I know what steps come next?

Relationships:

1. Do I recognize and/or smile when I see certain favorite people?
2. Do I have ideas and memories about fun things I did with certain people? (i.e., When I see Daddy, do I put myself near him and say "up" so we can play the same game we played last night?)
3. Can I calm myself down when I get upset or do I need help from someone else? (i.e., someone talking slowly and softly or rocking me)

Gross and Fine Motor Skills:

1. Can I independently move around my environment to explore things?
2. Do I have the upper body strength to support myself in a seated position?
3. Can I use two hands to explore materials and play with toys?

Surface Behaviors:

1. What do I do when I am left alone? (i.e., run back and forth, watch familiar tapes, play with toys)
2. What do I do with other people? (i.e., move away so they won't interfere with my play, hand them familiar objects)
3. What do I do if someone gives me something new and different? (i.e., throw it, explore it with my mouth and hands, bang it)

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel**. Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

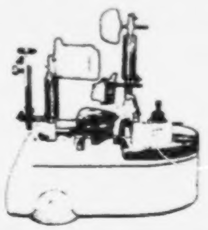
Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #41 or visit www.eparent.com/adinfo

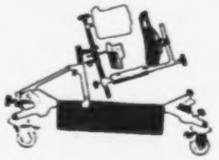
Early Childhood Mobility
Mini Go-Bot's

Century Stander



Stanford Standard
Note: Standing frames work with either Go-Bot

Yellow Go-Bot



GB-I Gait Trainer
(can be customized)

Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com

Circle #52 or visit www.eparent.com/adinfo

Guldmann
Ceiling lifts

Easy to use ceiling mounted transfer systems for physically challenged individuals

- Battery operated
- Used for lifting from wheelchair to bed, floor or bathroom facilities
- Used independently or with assistance
- Mobile floor models also available

Call today for a free evaluation of your transferring requirements and for the ceiling lift representative nearest you.

Guldmann, Inc.
1-800-664-8834
813-880-0619
813-880-9558 FAX

Circle #43 or visit www.eparent.com/adinfo

Naryan working with his therapist Chaye Lamm Warburg. Therapists can help produce a profile.

continued from page 62

gain more insight into how he feels and how we can best provide intervention. The box on page 62-63—Writing a Profile—offers some sample questions parents can ask themselves and others about each area of development.

Uses of a profile

A profile can be used in many ways. In general, the primary uses of a profile are to communicate information regarding a child and promote a deeper understanding of that child by other people in his life. Listed below are some specific ways parents and professionals have used profiles.

- Writing is an excellent tool to find, sort and organize your thoughts. The process of observing the child, analyzing what we see and asking ourselves questions regarding the child's strengths and weaknesses in each domain may help us gain a clearer picture of the interrelated development of the child. It also requires that we think about what it feels like to be this child. This can foster a more empathetic view of the child's behaviors.
- Sharing this profile with professionals in the child's life, such as teachers, therapists, family members and doctors, will help us communicate his behaviors, needs, feelings, likes and dislikes. It may also help the professional identify reasons for a particular behavior and what intervention strategies would be most effective.
- Parents, caregivers and professionals can work together as a team to generate answers to the questions on the template, thereby promoting a transdisciplinary understanding of the child.
- The profile can be used as a tool to communicate the child's

needs to family members who may not be directly involved in the child's day-to-day care. By conveying this information, the profile may influence the interactions of others with the child.

- A self-statement from the child and a photograph can be presented along with medical documents when submitting paperwork to insurance carriers or related agencies.
- When a child with special needs is being included in a regular education setting, parents of the other children in the class, as well as the children themselves, may need information in order to feel comfortable engaging and interacting with this child. Some parents have shared a profile of their child with classmates and their parents in order to foster greater understanding of "difficult" behaviors and facilitate peer interactions.
- The profile can be used during transitions between classrooms or schools. It has been used as a training tool for teachers, teaching assistants and personal aides as well as other team members.

Since the profile will change as the child grows and develops, each revision becomes part of a log of the child's development. The document is a snapshot-in-time that you can always review as needed. It is also a record of facts that might otherwise be forgotten. Therefore it also helps parents and others working closely with the child to step back and take note of the positive changes that are sometimes difficult to appreciate, particularly if they are subtle and have occurred over a long period of time. EP

Corinne G. Catalano is the School Psychologist at the Demonstration Program, Montclair State University, Upper Montclair, NJ and a graduate of The Institute for Infants, Children and Families in New York, NY. The Demonstration Program uses a DIR-based approach (Developmental, Individual-Difference, Relationship-based model) to work with young children, that is modeled primarily on the work of Dr. Stanley I. Greenspan and Dr. Serena Wieder.

Purnima Hernandez is a parent of a child with special needs in the Demonstration Program and is actively involved with her son's rehabilitation.

Patty Wolters is a Certified Occupational Therapy Assistant at the Demonstration Program.

email mobility@freedomconcepts.com

freedom what is your definition?

www.freedomconcepts.com

freedom has a different meaning for everyone. at freedom concepts we want to know your definition of freedom! we work with you, your doctor and your therapist toward a common goal, mobility. **talk to us, get our wheels turning** and we will create a custom **mobility** solution just for you! write us, email us, or call us today!

Featured photo rear steering assisted bicycle.

Freedom Concepts Inc.

1.800.661.9915

Circle #39 or visit www.eparent.com/adinfo

familiar faces

THE SHERMANS

Amin Sherman, 9, left, wrote to EP about his little sister **Cathy,** 7, who has difficulty walking; his brother **Colton,** 6, bottom right; and **Brenson,**17, who is blind. Amin enjoys watching movies with his brothers and playing Nintendo with Cathy.

DAVID

David Elimech, 11, is in the 5th grade. He receives a great deal of help and support at school, and goes to his special education teacher for math and language arts. His main diagnosis is non-verbal learning disability. He also demonstrates some aspects of autism. He is pictured here riding Caitlin at riding camp at a local farm.

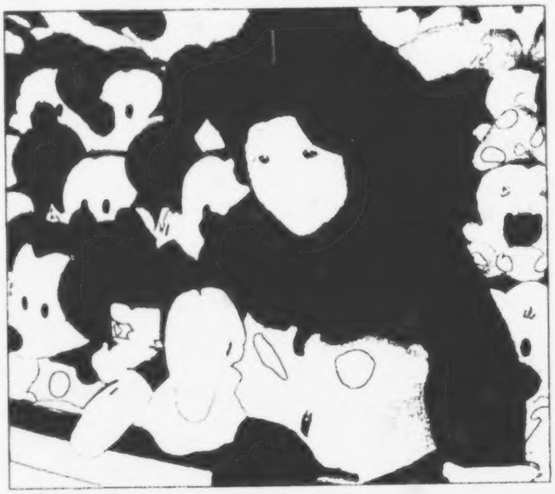
AUSTIN

Austin Douglas Weiss, 2, and his cousin **Brianna** share a hug and some colorfull stickers! Austin has congenital muscular dystrophy. He enjoys watching movies, playing on the computer and going for rides in the trailer behind dad's bike. He loves Barney, Blue's Clues and especially Bob the Builder.

ANDREW

Andrew Burgess, 5, and brother **Nick,** 10, are both accomplished swimmers and love to be under water. Drew receives speech, occupational and physical therapy. He also takes swimming, gymnastics and dance lessons. He even teaches Nick a few wrestling tricks! Nick enjoys racing go-carts, playing with Drew and making him laugh.

JORDAN



Jordan Tyler Pringle,1, loves to dance and learn new things. Jordan was born with Down syndrome and opsoclonus. His mom, MaryBeth, retired early to stay at home and provide special instruction. He is averaging a slight developmental delay with the efforts of a great team for his early intervention program. Jordan thrives from the stimulation and role modeling he gets from his siblings and parents.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (EXCEPTIONAL PARENT), 65 E. Route 4, River Edge, NJ 07661. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

ask the therapist

Moving Toward Mobility

Building skills and improving health by integrating a range of seating and transport options

by Ginny Paleg, MS, PT

Danny and Sue D write:

Our son Matthew is almost 10. He has learned to sit in a regular classroom chair independently, and he is able to walk across the room in his gait trainer. Yet we still need something to transport him in every day. We had a wheelchair with a headrest and a stroller with a solid linear positioning system. Both were too big and bulky and offered him more support than we felt he needed for short trips to the store. How do you feel about those lightweight, foldable transport chairs?

Ginny responds:

Sounds like you have an equipment showroom in your house! The professionals are in the midst of changing their opinions about how children with gross motor delays should be seated. In the past, we gave children as much support as possible. We emphasized comfort and bio-mechanical alignment.

> **We are learning to separate transport needs, sitting needs and how we view the postural needs of our children.**

It was common to see kids who had some sitting skills using a headrest, chest harness, seatbelt, abductor block, adduction guide, two sets of trunk support, Velcro® inguinal (groin-area) straps, and industrial-strength hook-and-loop foot straps. And of course, most kids were placed in a reclining position to make sure they didn't strain forward. This removed any chance of developing active muscle control. It also gave them a great view of the ceiling.

Lately, younger children—around 3 or 4 years old—are getting power systems. When they are in

continued on page 68

The comments on this and the following pages about wheelchairs have been heard from people around the world. Although compiled with tongue-in-cheek, there are some serious considerations here.

Top 10 Reasons Parents Don't Want Children to be in Wheelchairs

1. My child will not be part of a group, or run and play with siblings and friends.
2. Once my child is in a wheelchair, he is likely to remain in a wheelchair for the rest of his life. Hope is lost.
3. Wheelchairs dent the walls, doorframes and my shins.
4. Wheelchairs take up a lot of room and don't go up and down steps.
5. Pediatric wheelchairs are heavy and awkward for transport in a car.
6. I can't push a wheelchair and a grocery cart or a sibling's stroller at the same time.
7. Pediatric wheelchairs are not the right height for eating at the table with the rest of the family.
8. Pediatric wheelchairs are expensive so I can't afford any other equipment.
9. My child will be immediately labeled when he is in a wheelchair.
10. Children grow rapidly and pediatric wheelchairs need to be replaced every 2-3 years.

continued from page 67

environments where they can't use a power chair, they need something like a stroller or travel chair. The children sit in these for short periods of time, usually less than an hour. The strollers weigh 20 pounds or less, are easy to lift and fold up easily.

Most people sit in a variety of chairs in a variety of ways every day. Problems arise when a person stays in one position for extended periods of time.

Another change is how we see seating systems. We are learning to separate transport needs, sitting needs and how we view the postural needs of our children. When we drive in a car, you and I have a high headrest and use a seat belt. When we get out of the car, we leave these supports behind. Our children should be given this same option. Just because a child requires a headrest and chest support for the bus ride, he shouldn't be required to wear it all day long. Just because it's easier to get a child from the cafeteria to the library in a wheelchair, it doesn't mean she can't sit in a regular classroom chair like her friends when she gets there. Most people sit in a variety of chairs in a variety of ways every day. Problems arise when a person stays in one position for extended periods of time. Bones reshape according to the stress placed on them.

Top 10 Reasons Children Don't Want to be in Wheelchairs

1. I get left there.
2. It's hard to hold hands with my best friend while running on the playground.
3. No one can see the pockets on my designer jeans.
4. People look at me funny.
5. It's hard to get a cuddle.
6. No one will let me play with messy stuff.
7. I can't open the door and go through it.
8. I can't stare anyone down eyeball to eyeball.
9. No one will take my order.
10. My bottom gets tired.

Top 10 Reasons Professionals Don't Want Children to be in Wheelchairs

1. Bones deform.
2. Muscles wither.
3. The circulatory system is compromised.
4. The digestive and excretory systems are compromised when a person is sedentary.
5. Pediatric wheelchairs are too high for teaching pivot transfers. Caregivers have to lift the child's full body weight.
6. When reclined and leaning back against a headrest, the child can't learn or practice head control.
7. Lay people are hesitant to help people get out of a wheelchair; they fear that the child will get hurt. So, instead, the child spends the majority of time sitting.
8. Children are isolated from each other—they can't really get close.
9. If I have more than two students in wheelchairs, we can't go anywhere as a group without making a big production.
10. Young children gather information about themselves every day. If the child spends most of the time in a wheelchair, the child won't "think outside the box."

In this era of managed health care and dwindling health care dollars, we need to spend our money wisely. Perhaps every child does not need a $6,000 wheelchair at age 4. Maybe we should consider a transport chair, priced $400 and up, and put our money into a

ask the therapist

Ten Great Alternatives to Producing "Chair-Shaped" Kids

1. Consider using wheelchairs (or strollers) for transportation only. Provide alternative seating in homes and classrooms. Transfer skills will improve if they are practiced often.
2. Integrate supported standing into the natural sequences of everyday life. For bone health, the child should be weight-bearing at least 45 minutes and up to two hours per day. If the child is past infancy, teach sitting, standing and walking concurrently rather than teaching sitting first, then standing, then walking.
3. Practice range of motion as part of life. Have the child reach for the toothbrush, reach for the water faucet, reach for the book or the piece of fruit.
4. Teach the student to stand for diaper changes or for preparation to sit on the toilet.
5. Change your behavior so the child has the opportunity to learn and practice new skills.
6. Consider using a stroller rather than a wheelchair whenever possible. People are less hesitant to take a child out of a stroller. Supported sitting can be provided in an adapted chair. Usually scoliosis and joint deformities are the result of lack of movement rather than of movement activities.
7. Encourage people to help your child move, not just sit. Teach them how to help your child.
8. Write movement skills into your child's IEP as part of the educational activities, not as a pull-out activity.
9. Make self-initiated movement a part of your child's life, just as it is a part of your life.
10. Find out about a function-based program (like MOVE or Conductive Education).

versatile classroom chair and a stander that the child can move. Now we have spent less money and given our child more options for positioning.

Matthew was very lucky that you have been able to try so many different combinations of equipment.

> **Children do not learn to sit by being immobilized; they learn to sit by learning to coordinate muscle groups to reach and maintain balance.**

Somehow we have fallen into the trap of believing that children with severe motor disabilities should have one basic seating option. If you want your son to improve his sitting skills, you need to teach him to move out of balanced sitting and then find his balance again. Children do not learn to sit by being immobilized; they learn to sit by learning to coordinate muscle groups to reach and maintain balance. Chairs that offer supports should also have the option of easily removing the supports so the child can practice sitting skills for short periods of time many times a day. Of course, these practice sessions should be monitored for safety.

Although wheelchairs are a necessity for many people, they are not the only option in wheeled transportation. EP

In this column, Ginny Paleg, a pediatric physical therapist, answers questions from readers. Ginny works at The Hospital for Sick Children, in Washington, D.C. She specializes in treating children with developmental disabilities and neurological dysfunction.

Since Ginny has not assessed the child in question, parents need to review her suggestions with appropriate professionals. Mention of specific products, medications or treatment techniques illustrates suggestions; she is not endorsing any specific products.

Permobil Power Chairs

Modular Design Ensures Permobil Power Chairs Respond to Every Child's Unique Needs

When a child must use a wheelchair, mobility immediately becomes an issue of utmost concern. Believing that each child has unique needs is the reason that Permobil offers the **Playman/Robo™** and **Chairman KOALA™** pediatric power chairs, and the **MiniFlex™** seating system on its **TRAX™** and Chairman **ENTRA™** chairs. Owned by a private, non-profit Swedish foundation, Permobil has a worldwide reputation and a global impact. From the company's founding, Permobil has always believed that the chair must fit the user, not the other way around.

Permobil began as a challenge for one man

Permobil's beginnings date to 1963 when Swedish physician Per UddÈn heard about one of the first power wheelchairs from a U.S. colleague. At a time when the prevailing attitude was to ignore the existence of the handicapped, UddÈn believed that everyone had the right to live life to the fullest, and he requested one of the new wheelchairs for a patient.

The chair was a disappointment from the beginning. Barely working outdoors, it couldn't even manage interior door thresholds. When the supplier told him it was impossible to design a power wheelchair agile enough for indoor use but strong enough to use outdoors, UddÈn, with hospital machinist Bert Engman, began working in the hospital basement to prove him wrong. The first Permobil power chair, a huge advance in design, set the pace for innovations to come and resulted in pediatric power chairs with almost unlimited options.

The **Playman/Robo's** front-wheel drive allows the child to easily negotiate obstacles outdoors, and it has a nine-inch seat elevator that allows the child to easily reach higher objects. Its programmable **P&G Pilot + ™** controller allows adjustment of acceleration and deceleration to suit the child's driving ability; the **Omni + ™** alternative drive switch is optional. The joystick swings out of the way, making transfers as well as access to tables, desks and counters easier.

A second pediatric chair, the **Chairman KOALA**, is built with the same rugged motors and front-wheel technology as Permobil's adult power chairs but is scaled to fit the needs of a child. Compared to a standard rear-wheel drive chair, the **KOALA** base is only 22 inches instead of 26 inches and its length is 38 inches rather than 41 inches. The **KOALA** is easy to maneuver in tight spaces and is durable enough to withstand the needs of an active, growing child. Its proven front-wheel drive system climbs curbs up to 2-1/2 inches high and has pivoting rear wheels for responsive steering. All four wheels stay on the ground all the time.

The **KOALA** has the MiniFlex seating system, which allows the chair to grow as the child does. There are three different seat and back rest configurations, making it easy to change the seat plates and cushions as the child grows; in addition, the system accommodates other standard and custom-molded cushions. The seat height is fully adjustable and optional power seat adjustments (including power tilt and/or elevator) are available.

The **Playman/Robo** is one of Permobil's most innovative developments for pediatric clients. The **Playman/Robo** is designed so the entire seating system can be lowered to the floor at the touch of a button, which allows the child to play at the same level as friends and makes transfers to and from the chair easier.

The **MiniFlex** seating system is also available on the **TRAX** and **Chairman ENTRA** chairs. The **TRAX** all-terrain chair is Permobil's latest contribution to users interested in the great outdoors, with reliable, powerful, rear-wheel drive and a fully independent suspension for each wheel. The **TRAX** can climb obstacles up to six inches high and travel at speeds up to 5.5 mph for users under age 16. The suspension is adjustable to the user's weight, and the wheelbase can be adjusted to suit the terrain.

The **Chairman ENTRA** is Permobil's most economical power chair system. The **ENTRA** is narrower, shorter and weighs less than other comparable power wheelchairs, resulting in greater turning agility. With front-wheel drive, the **ENTRA** has a smaller turning radius than rear-wheel chairs. Its pivoted rear-wheel assembly ensures that all four wheels are always in contact with the ground.

Permobil offers countless options and four pediatric chairs because we believe keeping up with family and friends is especially important for children. To ensure the chair fits the user, every Permobil pediatric power chair is custom-made for a specific child to meet that child's unique needs. With a Permobil power chair, your child can enjoy a new freedom of movement and more independence.

This advertising supplement is sponsored and written by participating advertisers. It did not involve the editorial staff of Exceptional Parent magazine ©2002, Psy-Ed Corp.

"I feel good about permobil."

"I can see it in her smile. I can feel it when she puts her hand in mine – and even when she zooms off to play. I know we've done the very best we can for her. Her Permobil Koala is more than a wheelchair. Much more."
Uniquely capable. Uniquely your child's. Only from Permobil.

permobil

the art of mobility since 1968

To learn more about our complete line of the best in powered mobility, call **1-800-736-0925**. Or visit our website at **www.permobil.com**

Circle #65 or visit www.eparent.com/adinfo

Columbia Medical

Here's the challenge in a nutshell: your child is too tall or too heavy for their infant car seat. You still want positioning, support and of course safely for your child, even though they have outgrown their regular car seat. Fortunately, there is a product specifically designed to help you with this challenge: the **Columbia car seat.** This seat takes over where infant car seats leave off. Best of all, it not only fits larger and heavier children, but the **Columbia seat** provides an exceptional level of support and positioning. In terms of size and weight, the **Columbia car seat** fits children up to a tall 60 inches in height, and up to a heavy 102 lbs. These seats are fully crash-tested and government certified, meeting not only our U.S.A. standards, but also the tough Canadian and European safety standards. It is the only special-needs seat to meet these three key safety standards. But what good is a car seat to you if it doesn't fit easily in your particular vehicle? Fortunately the **Columbia car seat** has a unique design that makes for easy installation in any sedan, station wagon, hatchback, SUV, mini-van, pickup truck and even school busses. So versatile is the design that the **Columbia seat** even fits in coach-class airplane seats, so your child can fly safely on your family vacations. How does the **Columbia car seat** achieve a high level of positioning and support for each occupant? Firstly, it features a five-point harness. The five belts of this harness come together into a central release buckle, and the shoulder straps and crotch strap are softly padded for comfort and to prevent any chafing. Not only is the length of the straps adjustable, but the locations are adjustable to fit your child as they grow. Supplementing the harness are head pads. These are removable, and adjustable for height and width. Extra sizing pads that conveniently slide under the cover are included, for lateral support. An easily removable padded cover covers the seat. The cover's fabric is plush, soft nylon velour. You have a choice of three colors: blue, silver fox gray or dusty rose.

Naturally the cover is machine washable. There is a wide range of accessories available for the **Columbia car seat.** The range of accessories is constantly growing, and at present includes a seat-depth extender (to create an ideal fit for the largest children); a padded wedge to adjust the seat-to-back angle; a swing-away padded abductor; a buckle-guard (in case the child fiddles with the release buckle); and a height-adjustable tray. Because most children find the car seat so supportive and comfortable, their parents want to use the seat outside the family vehicle. To fill this need, Columbia offers the **Tilt-In-Space Mobility Base.** This accessory turns the car seat into an ultra-supportive stroller-like mobility unit. In the park, shopping at the mall, or anywhere a mobile support is needed, the **Mobility Base** fills the bill. The car seat attaches simply and securely to the **Mobility Base.** The seat may be set at any of three angles of recline on the base, for the most comfort. An adjustable footrest and folding design enhance the usefulness. Large wheels and casters mean easy rolling over uneven terrain. Finally, the modern design and pleasant colors of both the **Columbia car seat** and the **mobility base** make these products good-looking and attractive in any setting. These mobility products are in stock for immediate delivery.

472

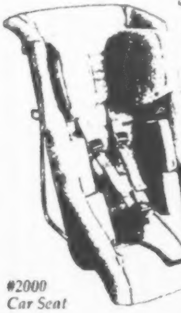
Sharing the Caring

Johnny, 51 lbs. and 48" tall, in the Columbia Car Seat

Columbia offers you solutions to the daily challenges of transporting, bathing and toileting your child – *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

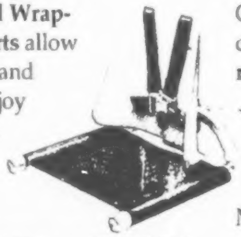
☒ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.-yet weighs only 11 pounds! It has been the No. 1 choice since 1986, for its adjustability and stylish comfort.



#2000 Car Seat

☐ At bathtime, our popular **Reclining Chairs** and **Wrap-Around Bath Supports** allow your child – and you – to enjoy the bath.

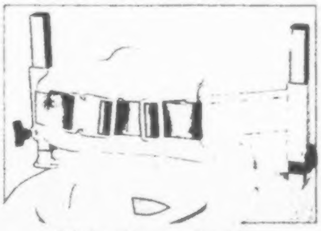
#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.



#7700 Hi-Back Wrap-Around Support

☐At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.

Why do these products work so well? Columbia products are thoughtfully designed, with each item available in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, tested and proven in real-life experience. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.



#4200 Small Support for children

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

473

COLUMBIA
SHARING THE CARING

Circle #26 or visit www.eparent.com/adinfo

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG
Columbia Medical Mfg. Corp., Dept D1, P.O. Box 633, Pacific Palisades, CA 90272
Visit Our Web Site at http://www.ColumbiaMedical.com

473

Freedom Designs

IN PURSUIT OF EXCELLENCE

We at Freedom Designs, Incorporated, have been involved in manufacturing seating systems and components since 1982. we have an ongoing commitment to quality of product, customer service, delivery time and representation. The vision of excellence extends throughout every phase of order, production and delivery, to ensure you and the end user of the finest product available.

We have a strong commitment to being the leader in the field. We are guided by the needs of the marketplace, by you, the Rehab technology Specialists and therapists. Our unique products are the result of input by industry professionals and our engineering team consisting of a mechanical engineer and an aerospace enginer. With this perspective, and an in-house machine shop, we are able to design the most functional, durable and cost-effective products. With our computerized design capability, we continue to develop better parts, while realizing manufacturing economies, which we can pass along to you.

Our pursuit of excellence also extends to supporting our dealers and therapists. We are involved in an education program, offering CEUs (Continuing Educatoin Units), as well as ongoing training in a field that is rapidly changing.

Our vast line of products, plus our ability to do custom orders, offers state-of-the-art solutions to your difficult seating problems. We thank you, our customers, for your support in the past and look forward to continuiing to serve you.

We make more than parts, we make a difference!

Giiny Maloco—President.
Freedom Designs, Inc.

"Libre Folding Tilt"
with Swing Away Hangers

Introducing the new, versatile Spectrum Libre Folding Tilt frame which has the capability to laterally fold, tilt up to 45 degrees and the option of swing away/removable hangers. Any Freedom Designs, Inc. seating mounting hardware can be adapted to this innovative frame. Highlights include: anodized vibrant colors, 75 or 90 degree swing away hanger options, variety of footrest options attached to the frame and backpost mounted armrest options. This versatile frame comes in widths of 10" to 18" and seating depths of up to 20" deep. Let the new Spectacular Spectrum Libre Tilt give you the freedom you've always wanted in a wheelchair frame.

BEST COPY AVAILABLE

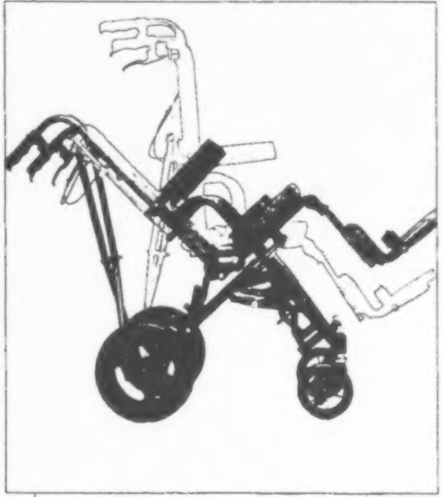
FREEDOM DESIGNS INCORPORATED

www.freedomdesigns.com

2241 Madera Road, Simi Valley, CA 93065 - 805-582-0077 • 800-331-8551

Circle #40 or visit www.eparent.com/adinfo

Convaid



For over 25 years, Convaid has been dedicated to helping children with special needs. Our mission is to be sensitive to the broad needs of physically challenged children and, just as important, to the needs of the caregivers. We aim to provide the best combination of corrective positioning, comfort, durability and safety for the child in a product that is both attractive and convenient to use by the caregiver.

Convaid wheelchairs and strollers are best known for their lightweight and compact-folding features. Our chairs are constructed of lightweight materials, and our patented compact folding mechanisms allow our products to be easily carried up steps, placed in the trunk of a car or taken on buses, trains or planes. We took on the challenge of including this important feature on our tilt-in-space positioning chair, the **Safari Tilt.** This resulted in the world's first compact-folding tilt chair. A second folding tilt, the **Rodeo,** has now joined the lineup.

We manufacture five basic chair structures in a variety of sizes and models with dozens of optional features available. This results in a choice of more than one hundred chairs in a variety of colors.

Since 1990, Convaid has been an industry leader in crash testing wheelchairs for tie down in a bus or van. Our chairs are formally tested at a nationally known university, and are proven safe for motor vehicle transport. They tested to exceed the minimum legal safety requirements, as well as meeting voluntary safety standards such as WC-19.

Convaid continually strives to develop innovative new products, and considers it a privilege to serve children with special needs and their caregivers.

More Smiles

New & Improved

Safari Tilt

When you talk...

we listen

The new and improved Safari chair is something to smile about.

- New instructional video*
- Improved fold
- New style heel loops
- Optional recline, 5 - 45 degrees
- Easy to tilt
- Crash tested

*Ask for free introductory video

Convaid

Circle #28 or visit www.eparent.com/adinfo

PO Box 4209, Palos Verdes, CA 90274 USA ◦ Tel 1-888-CONVAID (266-8243) / FAX 310-618-8811 www.convaid.com

Sammons Preston

There is a growing trend in the healthcare products industry that sees American companies bringing innovative designs to the U.S. market by establishing relationships with their European counterparts. As international trade barriers continue to drop, American companies are capitalizing on the fact that most European countries spend proportionately more than the U.S. to provide medical products to their citizens.

A progressive example of this trend is Sammons Preston, the manufacturer of **Tumble Forms** positioning products. The Bolingbrook, Illinois-based healthcare products provider has developed an ongoing relationship with Alvema, a Swedish manufacturer of pediatric seating and positioning products. "Sammons Preston has long been a leader in providing unique seating solutions," notes company group product manager Mike Gravel, "and the Alvema line has added to our depth." Sammons Preston has recently announced the introduction of the **"Mio,"** a new mobile positioning system from Alvema. The Mio is unique in its ability to adapt to multiple bases. It can be purchased with either a stroller base, or a mobile indoor high-low base. The seat itself has a great degree of flexibility, allowing the positioning of clients with mild to complex seating requirements, who are 3 to 13 years old.

It is the high-low base, however, that makes the **Mio** special. This base is designed for indoor use and adapts to all the tasks that indoor living requires. It can be lowered to floor level to allow the child to interact with his peers, or it can be raised up for feeding or work at a computer. The **Mio's** height adjustment takes little effort and is accomplished with the aid of a foot-activated gas spring. And if you are looking for mobility outside of the house, the **Mio** easily comes off the High-low base and snaps into its stroller base.

"Will the seating system grow with my child?" This is one of the questions asked most often by parents of special needs children. The **Mio** appears to tackle this task in a very effective way. The seat back adjusts in height, depth, and angle. It has the unique ability to fold absolutely flat, allowing parents to place their children in a full recline position. The **Mio** has adjustable trunk and hip supports to position the child securely, and a footrest that adjusts in both height and angle. Once optimal positioning is achieved, the entire seat can be tilted in space by squeezing a simple adjustment lever. And if the parent prefers to face their child, the entire seat can be lifted out and reversed in the stroller frame.

Bulky, difficult-to-store equipment is one of the bigger challenges facing parents of special needs children today. This is particularly true when the child must be transported. Often parents are forced to purchase expensive minivans just to be able to get their child from one place to another. Equipment that folds and stores compactly is an invaluable tool for parents and caregivers. One of the reasons Sammons Preston added the **Mio** to its line is the **Mio's** ability to fold compactly. In fact, when installed on the stroller base, the entire **Mio,** including the positioning seat, folds small enough to fit into any standard car trunk. Quality engineering is clearly the driving force behind the **Mio** design.

Strength, durability , and ease of adjustment are goals the **Mio** achieves with little effort. When the engineers at Alvema were designing the Mio, they decided to add one last, very important feature: bus transport. When parents spend a great deal of time and money selecting the right seating system for their child, they expect it to meet as many of their child's functional needs as possible. Transportation to school is a fundamental task that is made infinitely more simple when the child does not need to be taken out of the seating system. With this in mind, the engineers at Alvema designed and crash tested the **Mio** for transportation on a school bus using a standard five point tie-down system. These are only some of the features that are making the Mio a popular American product with a European flair. For more information, call Sammons Preston at 1-800-323-5547.

478

no more frustration - just fun

LECKEY®

Advance Bath Chair

New Design

The most extensive height range and adjustable seat angles make bath positioning easy.

Extra-soft mesh material and padded support bars give your child a more comfortable and enjoyable bath time.

Take the Advance Bath Chair from the tub to the shower with the optional trolley

Also available is the Basic Bath Support that provides adjustable positioning angles at a fixed height.

And The FUN Doesn't Stop There

Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Call us today for more information.

- *Lighter mobile bases*
- *More adjustable components*
- *Peer level positioning*
- *Child friendly positioning straps*
- *Playful colors*

Pronestander

Freestander

Totstander

Toilet/Shower Chair

Easy Seat

SAMMONS® PRESTON
an AbilityOne

Leckey® products are brought to you exclusively by Sammons Preston®

Start the fun today! Contact your local Sammons Preston distributor or home health dealer for more information.

Or call Sammons Preston at
1-800-323-5547

Circle #70 or visit www.eparent.com/adinfo

Otto Bock Health Care Pediatric Postural Mobility Systems

Functional & Fun!

When you think about choosing a postural mobility system for your child, you want a product that has a proven record of reliability – something that gives your child the support they need, that is durable enough to last a long time, and can grow with your child. You also think about features that help you as a caregiver; a system that folds easily, is easy to lift, and a pleasure to look at. The **Lisa stroller** by Otto Bock Health Care combines all these features and more in a functional and fun mobility system.

The **Lisa** was developed for a child requiring mild to moderate positioning assistance. We offer a large menu of optional fitting accessories like headrests, positioning harnesses, and abduction blocks to accommodate a variety of specific positioning needs. The **Lisa** also has a unique backrest recline that can be set at any angle between 90° to 130°, enabling it to suit a number of hip positions.

Keeping in mind that your child is likely to grow, the **Lisa** can grow with your child: the stroller comes in 2 sizes, each with seat depth adjustability and optional backrest extensions and hip width reduction pads. These features enable you to customize **Lisa's** fit to your child and accommodate growth without sacrificing fit.

While providing optimal fit and positioning support, the **Lisa** also boasts great visual appeal. The stroller is available in two, kid-friendly colors and accessories come in coordinated fabric prints and solid colors. The **Lisa** is also caregiver-friendly. Unlike other strollers, **Lisa** has a special scissors & slide design that reduces it to a folded length of 42" or less, so it fits easily into most car trunks. The Lisa is also lightweight and easy to lift.

Most important, the **Lisa** offers maximum stability and strength. The stroller is a powder-coated aluminum frame and its various sections are attached with screws instead of rivets. The seat and back are made of fiber-filled padding with nylon covering. They are reinforced for increased support—no "hammocking" effect in the seat, which can compromise a child's position. We're so confident in this product that we back it with a 5-year warranty.

Joining the other products in Otto Bock Health Care's pediatric mobility product portfolio—the **Kimba tilt & recline system**, the **Bugsy posterior walker**, and the **Spee-Dee gait trainer**—the **Lisa** shares attributes that are the hallmarks of our products: durability, design, and positioning components for each child's specific needs.

Otto Bock Health Care was established in 1919 and has since grown to be the world's leading supplier of prosthetic and orthotic components. Our mission statement commitment is to enhance the agility, mobility, comfort, and confidence of our patient customers. We take this commitment very seriously and believe you'll recognize the results once you see the **Lisa**. Additionally, we offer professional support and education through our Professional Services team, a group of clinically trained individuals committed to ensuring that our dealers and customers are satisfied.

If you are looking for quality, durability, and an experienced company to back up their promises, call us at Otto Bock Health Care. For a dealer near you, call us at 1-800-328-4058.

Specifications

Dimensions & Weight Size I (for ages approximately 3-8 years) Size II (for ages approximately 6-16 years) Seat depth 10" - 12" - 14" 12" - 14" - 16" Seat width (with upholstery) 12" 14" Seat width (without upholstery) 14" 16" Back height (with extension) 21" (27") 23" (29-1/2") Distance from seat edge 9" – 15" 10-1/2" – 15" Weight 24 lbs. 34 lbs. Maximum weight load 88 lbs. 110 lbs. Folded dimensions 41"x11"x13" 42"x16"x17" Tire diameter – front/rear 6"/8" 7"/10" Back angle of recline 90° - 130° 90° - 130°

PEACE OF MIND

When it comes to your child, you don't compromise. Safety is indispensable. You demand quality. Reliability. Functionality.

The Lisa pediatric postural mobility system from Otto Bock gives you all this while maintaining its playful good looks. So go ahead. Take it "off sidewalk". Recline the back rest up to 130°. Accessorize to your heart's content. And enjoy how easily it folds and how little it weighs. You and your family deserve it.

For more information, visit www.ottobockus.com, or call 1-800-328-4058 to find a dealer near you.

Otto Bock
HEALTH CARE
www.ottobockus.com

Circle #64 or visit www.eparent.com/adinfo

Quantum Dynamo Power Chairs

Let Children Enjoy Life to the Fullest

Dubbed "the power chair for playing," the **Quantum Dynamo** power chair line is giving children the opportunity to simply be children, sometimes for the first time in their lives.

Manufactured by Quantum Rehab, a division of Pride Mobility Products Corp., the **Quantum Dynamo** power chair line serves the needs of children with varying disabilities, focusing on a child's desire to be an active member of his family and circle of friends.

While the **Quantum Dynamo** offers many features that allow for easy maneuverability in the home, at school or on the playground, parents and children prefer the **Dynamo** for its non-medical, aesthetically pleasing design, outstanding indoor and outdoor performance, and the variety of vibrant, child-friendly colors available.

"The **Quantum Dynamo** line takes away the stigma of being in a power chair," says Scott Higley, National Sales Manager, Quantum Rehab. "The **Dynamo's** design and performance capabilities allow children to keep up with friends in a variety of environments, from the tight corners of the classroom to the playground and ball field."

Positive Outcomes Thanks to the Quantum Dynamo Line

Luke, a young boy with muscular dystrophy, experiences the benefits of using a **Quantum Dynamo** every day. Thanks to the **Dynamo** he affectionately named "Buzz," Luke is able to play soccer and other sports with his brother and friends. Luke's mother, Diane, sees the positive impact this power chair has on her young son's life, returning him to his happy, easygoing personality. "It allows him to be a kid again," she says.

Craig, a six-year old boy from the Washington, D.C. area, was diagnosed with type III osteogenesis imperfecta, a debilitating bone disease. During his first power chair evaluation at the Hospital for Sick Children in Washington, the seating clinic therapists recommended that Craig try out a **Quantum Dynamo** power chair.

The seating team members and Craig's mother were immediately impressed with the results of the trial. The **Dynamo's** versatility, including the compact, maneuverable base with a disassembly feature for transportation. The ability to upgrade to a power tilt seating system and the option for a variety of specialty controls to operate the chair, made it the perfect choice for Craig's size and medical condition.

Features and Benefits of the Quantum Dynamo Power Chair Line

The **Quantum Dynamo** line features the **Dynamo** and the **Dynamo ATS** power chairs. Both models come standard with Pride Mobility's **Versa Seat** seating system, a modular seating framework that adjusts in width and depth as the child grows. The **Versa Seat** accepts specialty cushions for pressure management and offers a manual recline option.

The **Dynamo ATS** comes standard with **Active-Trac Suspension,** further enhancing the chair's outdoor capabilities allowing children to play on rougher outdoor terrain.

The **Dynamo** line accepts a variety of specialty controls, as well as seating systems as small as 10 inches wide by 10 inches deep that can expand as the child grows.

Dual foot platforms are available on the **Dynamo** and the **Dynamo ATS,** providing a means of transfer while offering support for shorter leg lengths.

Both models come standard with 10" knobby drive wheels and Pride Mobility's patented mid-wheel drive technology to give children superior traction outdoors as well as tight-quarter maneuverability indoors.

Available shroud colors include Bronto Blue, T-Rex Red, Gator Green, Primitive Purple, Saber Yellow and Prehistoric Pink.

For more information on the **Quantum Dynamo** power chair line, please call Quantum Rehab toll-free, 1-888-813-4081, ext. 1006.

QUANTUM™ DYNAMO®

The Quantum™ Dynamo® series offers children fun, independence and confidence in their abilities. With Quantum Rehab's patented mid-wheel drive performance, children can play, explore and keep up with their friends.

- Kid-friendly styling and six all-new fun colors that allow children to express their own individuality
- Compact size delivers easy turning, even in kid-sized spaces
- Achieves sizes as small as 10" x 10" with Versa Seat and 12" x 12" with power tilt
- Seat-to-floor heights as low as 15" - perfect for maneuvering under school desks
- Available dual platforms provide easier transfer and extra support for shorter legs
- On-board battery charger for added convenience
- Disassembles for easy transport

QUANTUM

LEAPING AHEAD WITH MORE ADVANCED REHAB PRODUCTS AND SERVICES

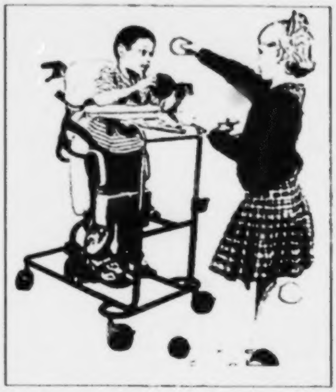
(U.S.) 1-866-800-2002 • (Canada) 1-888-570-1113
www.quantumrehab.com

Circle #66 or visit www.eparent.com/adinfo

Directory of Special Mobility Advertising Section

Circle #	Advertiser Name	Page #	Circle #	Advertiser Name	Page #
17	Altimate Medical	85	64	Otto Bock	81
22	Body Point Designs, Inc.	91	65	Permobil	71
26	Columbia Medical	73	66	Pride Mobility	83
28	Convaid	77	67	Real Design	99
	Cycletote Corp.	89	70	Sammons Preston	79
38	Frank Mobility	95	76	The Baby Jogger Company	87
40	Freedom Design	75	82	Wenzelite Medical Supply	97
48	Hertz Supply Co., Inc.	93			

Creating Inclusion by Standing



Making your classroom inclusive does not have to be a difficult task. Many therapists and special educators have found that when their special needs students stand throughout the school day, those students are more responsive, and feel like they are included more in the daily activities. They experience a change in their special needs students who stand that also carries over to the child's home.

*"The **Mobile Magician** is perfect for Tyler's activities. He loves the mobility and he can eat, play, watch TV or, most important, do his homework."*

T. B.—Kansas City, Missouri, USA

School therapists and educators love the **EasyStand** 7000 Magician and EasyStand 5000 Youth standing products. Why you ask? One reason is that our pediatric and youth standing products can also be used as a desk in the sitting position. This alone makes the **EasyStand** a great solution for the classroom, because kids can sit or stand in the **EasyStand,** with full access to the tray. When their peers are sitting at their desks, so can the special needs students. When everyone else is standing, a child who is usually sitting in a wheelchair can also stand up and be part of the crowd.

"Michelle can also use it as a classroom desk. It's very easy for one person to position her and get her up to standing without the risk of injury."

S. K.—St. Cloud, Minnesota, USA

Teachers, professionals and aides love the easy one-person transfers via sliding or the standing pivot method. Kids also feel more at ease because they are being transferred from their wheelchair to another level seated surface. After they are secured, a teacher or aide can gradually lift them into the position they desire, which can be anywhere between sitting or standing.

*"We got the **Magician** because we wanted to avoid the extra lifting needed with other standers. We were also impressed with the many possible positions between sitting and standing."*

H. T.—Boca Raton, Florida, USA

Another reason why the **EasyStand** is so popular in schools is because of the gradual transition from the natural sitting position to the upright standing position. This normal positioning allows for a decreased student fear factor and, the **EasyStand** can stop anywhere between sitting and standing to accommodate for tight hamstrings and contractures. Many therapists like to position their kids in a neutral position, so that the child's weight is equally distributed between the feet and buttocks.

*"With the **Magician** we have the ability to change positions of our students in one piece of equipment."*

D. D.—Albany, New York, USA

"The ability to go from sitting to standing is a plus. Also the ease in putting him into it with just one person is a welcomed benefit."

N. P.—Evansville, Indiana, USA

Since **EasyStand** products have a clear desk table, students can stand as they do school work or fun activities. What does this mean for therapists, parents, and teachers? One advantage is that IEP Goals of standing can be accomplished right in the classroom while the student learns or plays. The **EasyStand** also has the adjustability and support options to fit many students' needs. With only one stander, many of your students can stand safely with the support options they need and a fit just for them.

*"The **EasyStand** is the most versatile and suitable product for our diverse population."*

P.T.—St. John, NB, Canada

*"My daughter feels very safe in the **Magician.** She likes to stand and she is not afraid. This is a big improvement from our previous experience with standing."*

S.M.—Manchester, England UK

The benefits of standing can be physical as well as emotional, and kids of all ages can benefit from standing at school, home, or therapy. Medical professionals around the world have prescribed the EasyStand for their clients so they can enjoy health benefits such as improving range of motion, decreasing contractures, decreasing pressures sores through position changing, improving circulatory and respiratory functions and more.

*"We chose the **EasyStand** Youth post-operation to regain and strengthen leg use and development, and to receive other benefits. Laura loves being upright."* L.V.—Coolbinia, Australia

"With this stander I don't have so much extra lifting like the others. Jack gets more range of motion and weight bearing too!" H. P.—Largo, Florida, USA

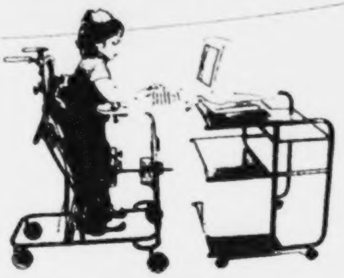
Inclusion by standing is achievable when you are using **EasyStand** products. For more information, contact Altimate Medical Inc. at 800-342-8968 or visit www.altimatemedical.com

Standing Small, Growing Tall

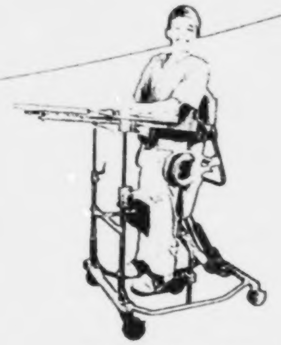
Classroom inclusion is now achievable! With the EasyStand, kids can sit when their classmates are sitting and stand when they are standing. The EasyStand line of pediatric & youth standers is perfect for home and school. From early intervention through high school, we can stand all your students.

Call today for more information on how to ***try one free!***

EasyStand Magician-ei
Height Range: 28"-40"



EasyStand 7000 Magician
Height Range: 36"-54"



EasyStand 5000 Youth
Height Range: 4'0"-5'6"

AltimateMedical
262 West First Street Morton, MN 56270

800•342•8968 507•697•6393
www.easystand.com

EasyStand®

Circle #17 or visit www.eparent.com/adinfo

FREEDOM

- **Manual & Power Wheelchairs**
- **Scooters • Standers**
- **Gait Trainers • Enclosed Beds**
- **Sales, Service and Repairs***
- **FREE in-home evaluations***

3rd Annual Wheelchair and Mobility Expo
June 22, Newington H.S., Newington, CT.
Free Admission. Info (860) 666-8888 ext 301

* Serving Connecticut & Eastern Massachussetts and the New York Capitol region only.

CR CONNECTICUT REHAB
& MEDICAL PRODUCTS

1-800-457-3422
www.ctrehab.com
11 Progress Circle
Newington. CT 06111

Baby Jogger

Why the Special Needs 5 Stroller is Really Special!

We've always been known for our **Baby Jogger** strollers, but a little-known fact is that for a long time, we have been making wonderful strollers for disabled children. This is one of the very best parts of our company; because we manufacture in America, our production shop is able to customize to whatever the parents feel is best for their child.

I still remember the first time we built a stroller for an older special needs kid. His mom called me from the ranch they lived on in Colorado. It was a real working ranch, up in the mountains. She explained that once the snow hit, she was stuck in the house with her son, because his expensive wheelchair just couldn't go through the snow. She asked me if we could build something that would let her and her son goes outside in the winter. I asked if their roads were plowed, and they were. So I told her, "If you can walk on the snow-packed road, we can build a stroller that you can push." I will never forget it, because she started crying. And later she sent pictures of her and her son, happily out in the snow.

I was pretty sure of this, because I had my two toddlers, and was pushing them in the first **Twinner** we ever built, on our snowy country roads. My kids loved it. They were all bundled up, and would howl in protest when we turned around to head home.

So we built that first stroller. Then another. Then for quite a while, we were building **Baby Jogger**-like rolling bases, and we would make sure they would accept the seat insert from the wheelchair.

Since we were new to this (in the late 80's), we were very cautious. We started to ask that while we would build whatever they wanted, and we would guarantee that they would be happy with it or there was no obligation, but we did want them to take it into their doctor or therapist for evaluation. So every stroller for **Special Needs** kids that we built, was signed off on by a medical professional. This was invaluable for us, because first we had to meet the needs of the child and the parents, who know what they wanted; but then we were able to get valuable feedback from the medical professionals.

We started to compile info; we visited seating clinics around the country, even places like John Hopkins and the Stanford Medical Center. We started to see patterns in what customers needed, and came out with the **Special Needs 1** stroller. It was just a bigger **Baby Jogger.** Then we learned more and made the **Special Needs 2**, which was more customized for disabled children.

Most of our kids had cerebral palsy. We found that they often slept in a normal bed, and rode in a car with the usual seat. So we were seeing that these kids often reported that they were more comfortable in our cordura sling seat, which hugs the body just like resting in a hammock. So we did less of the rolling bases, more of our own **Special Needs** line.

Today our ability to help **Special Needs** kids is at an all-time high. We have our new Special Needs 5. This stroller folds much easier, making shipping and travel much better. Parents can add on a highback addition to the seat years later, expanding the length of time that the Special Needs 5 will fit their older child. We have an optional footwell, which helps those longer-legged kids, and this can be added at any time. Our best stroller if you also like to run with your kid.

What we really like is that these strollers make the whole family happy. The wonderful kids who use them tell their parents that the really like the bright colors, because it doesn't look medical. This year our colors are Teal, Jade Green, Sapphire, Red, Purple and Navy.

My favorite part is that we have wonderful swivel wheels available now. These actually swap out! So the stroller can have our three big wheels, for going hiking on sand or snow. It can change in a heartbeat to the swivels in the front, so that for home or school, or out at a mall, you can push a very heavy child easily.

Another cool new stroller is our **Custom Seat Adapter** on our **Special Needs 5** frame. If your child needs to be in a molded insert or specialized wheelchair seat, we can work with that manufacturer, and build a **Baby Jogger**-like base that the wheelchair seat can fit into.

One of our most fun adaptations is our **Specialty Two.** I always want to call it the Granny Jogger, because our photos show my mom Judy, in her 70's, in it. We originally designed this for the Disney parks, who requested a stroller that could hold two children, or one disabled adult. It is so much fun to sit in! You can just sit in it for hours and read a book, it is like a hammock on wheels! We had a friend in it who is close to 300 pounds, and pushed him around a trade show for hours. Like the **Special Needs 5,** it has heavy-duty swivel wheels in the front. A great stroller for casual, fun days.

Our **Special Needs** line is approved for Medicaid and we can help parents put it through their insurance company. Usually we can put them in contact with a local physical therapist or medical store if they would like to go in to try the stroller (they tend to be set up for insurance). Or we can help from here, and if your insurance for a "rolling base" is already committed, we can help families with our easy payment plan.

With our Lifetime Warranty, and the fact that the strollers are satisfaction guaranteed, our commitment to our customers is made very clear. We only succeed if everyone is happy with the stroller, and it is comfortable, fun, and safe.

What's next? We are working on an awesome new stroller, that has the ability to carry either a teenager or an adult. Please look for us at the Abilities Expos; we would love to meet you!

Mary Baechler, President
The Baby Jogger Company

The BEST strollers in the WORLD!
by Baby Jogger

Comes with Swivel and 3-wheeled configuration

Highback seat for tall kids available!

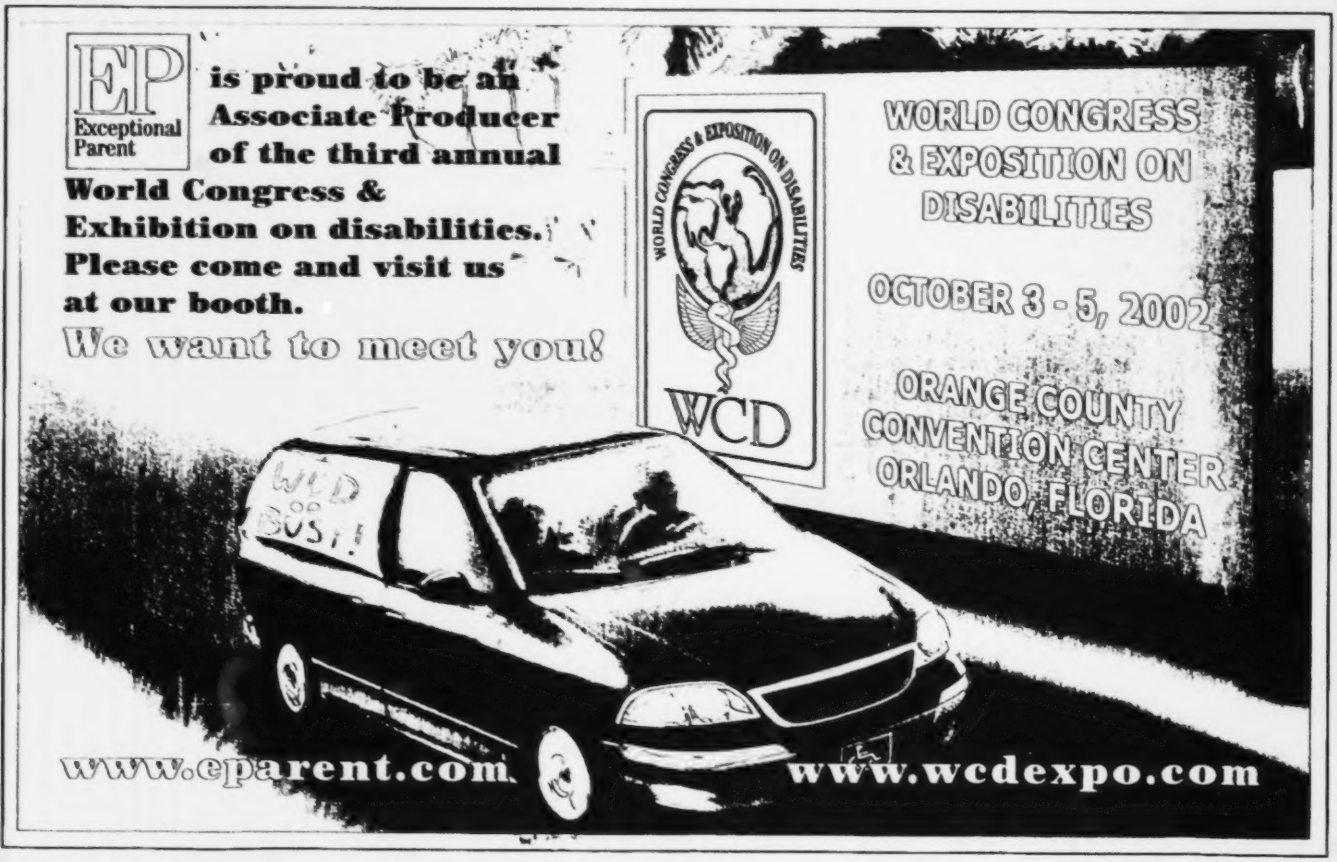
Presto Chango!
Wheels can be swivel or big front wheel

Quick, easy, compact folding!

- Affordable
- Folds Compactley
- Holds up to 150 lbs.

BABY JOGGER®
www.babyjogger.com • (509) 457-0925

Circle #76 or visit www.eparent.com/adinfo



EP Exceptional Parent is proud to be an Associate Producer of the third annual World Congress & Exhibition on disabilities. Please come and visit us at our booth.
We want to meet you!

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD
WORLD CONGRESS & EXPOSITION ON DISABILITIES
OCTOBER 3 - 5, 2002
ORANGE COUNTY CONVENTION CENTER
ORLANDO, FLORIDA

WCD OR BUST!

www.eparent.com
www.wcdexpo.com

Cycletote

The CycleTote Difference

Most bicycle trailers are assembled with plastic or nylon fasteners, use 20 inch wheels and a side-pull chain stay hitch. **CycleTote** alone, with its TIG-welded aluminum frame, full sized (700c or 26 inch) bicycle wheels, a center-pull hitch, and an extremely low center of gravity, has achieved a superb combination of pulling ease, sweet trailing, and ground-hugging stability. It just feels better.

You can actually feel this difference the moment you begin to pull a **CycleTote**. And with average loads the trailer has little or no effect on cycling mobility, allowing you to maneuver your bike normally for a truly enjoyable ride.

The optional automatic braking system is equally superior, providing a safer, more uniform reduction in speed - especially important for emergency stops, with heavier loads, or at higher speeds.

CycleTote performance, together with the strongest protective roll cage and perfectly fitting safety harnesses, earned recognition by Eugene Sloane, best selling author of "The Complete Book of Bicycling" as "far and away the safest child carrier." Tandem Magazine called **CycleTote** "the Lexus of bicycle trailers." "While I don't have any children for it yet, this is the trailer I would entrust with my kids."

Quality and durability are guaranteed by a Lifetime Frame Warranty. And with the option to convert between uses as your needs change (children, cargo, pets, touring, grandchildren, etc.), you're ready for a lifetime of use.

Try one, compare it, and see for yourself. There is no risk. If you don't agree that **CycleTote** is best for you, or if for any reason you just decide not to keep it, call us within 30 days. We'll pick it up and give you a complete, no hassle refund.

This was written at about the time we were introduding the **Special Needs trailers** and is in reference to the rest of **CycleTote**'s family of trailers. Before that some would respond to our boasts of superiority with chuckles and remarks that all trailer companies claim to be best. There is a noticeable change today, especially among those who have had a chance to review our web site. Three factors are key: 1) the foregoing explains why **CycleTote** is better, 2) many testimonials attest to the accuracy of our claims, and 3) we back it up with our satisfaction guarantee.

How well do **CycleTote** trailers meet the elevated expectations of purchasers? We judge this, not only by the glowing comments received from customers, but by the number of trailers actually returned under the guarantee. We're proud to report that returns have hovered around the one percent level for the past several years, and most of these have resulted from an unappreciative canine's failure to share the master's enthusiasm for cycling. Never has a **Special Needs trailer** been returned.

Are the points covered in "The **CycleTote** Difference" also applicable to the **Special Needs trailers**? Knowing that bigger trailers are more cumbersome and that pulling ease and stability are reasonably diminished by increased weight and a higher center of gravity, the advantages of full-sized bicycle wheels and a center-pull hitch remain quite apparent. You'll still feel and appreciate the difference. With more weight to pull, the automatic braking system can assume even greater importance. The design of the **Special Needs trailer** and its roll cage attest to a continued emphasis on safety. And the lifetime warranty and satisfaction guarantee are still fully applicable. So with reasonable adjustments for the increased size, weight and strength of the **Special Needs trailer** the advantages described in "The **CycleTote** Difference" very much apply to the Special Needs trailers.

There is no greater gift than that of freedom and happiness. And there can be no greater gratification than hearing the squeals of delight when a daughter is getting ready for another ride in her **CycleTote** Special Needs trailer. One who has been so rewarded has agreed that we can share some of his happy times with you:

> ***"It has been 3 years since I bought the special needs trailer for my daughter. We have traveled countless miles without incident or problems, not even a flat. It would be difficult to translate all that tire wear into the fun and pleasure we have had with the trailer. It certainly opened up an entirely new world for my daughter that otherwise she would never have experienced. We can take our goodies and treats and make a day of having fun. In all honesty, my daugher smiles, laughs, etc. the entire time she is in the trailer. She never wants to stop and never tires of riding. I can't imagine ever being without the trailer."***
>
> **—Dennis Foster, Fairland, OK**

488

Enjoy the out-of-doors together with a

CycleTote® Bicycle Trailer
Running Stroller

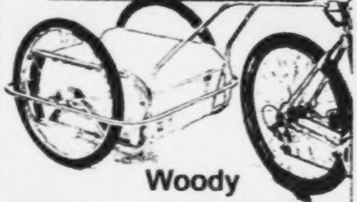
1-800-747-2407 www.cycletote.com

Satisfaction Guarantee/Lifetime Warranty

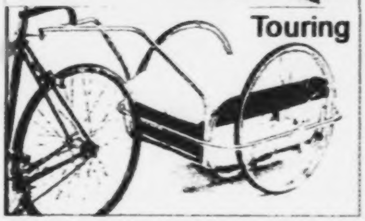
More *CycleTote®* Trailers

Family

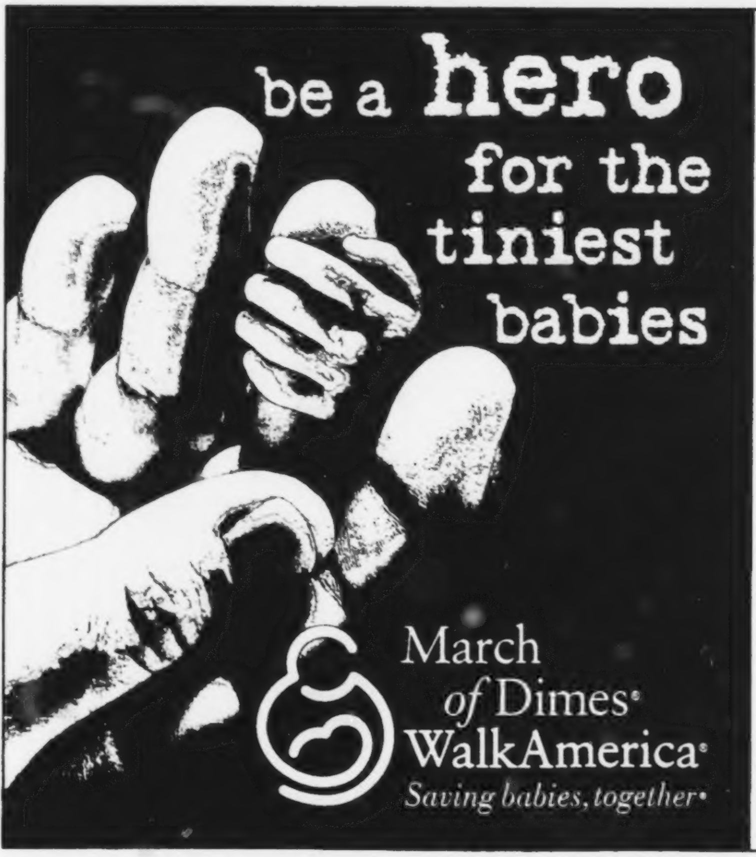
Doggy Tote



Woody



Touring


be a hero
for the
tiniest
babies
March
of Dimes®
WalkAmerica®
Saving babies, together®

Every year, nearly half a million babies are born too soon, some so small they can fit in the palm of a hand. Many have to struggle just to survive. Join March of Dimes WalkAmerica and help give tiny, premature babies a fighting chance. Maybe even a baby you know.

Call 1-800-525-WALK or visit **www.modimes.org/walkamerica** and register today. For more information call your local March of Dimes chapter.

This space is contributed by the publisher.

Well Equipped–Designed to Travel

By Trudie Read, OTR/L

The **Lex EASyS**, Ergonomical and Adjustable Safety System for Rehabilitation Strollers, is a revolutionary positioning system that is cleverly disguised as a stroller. The aim of its stylish design is to increase acceptability and promote early intervention, for children from 6 months up to 12 years old. 'An ounce of prevention is worth a pound of cure'.

The unique and patented **Balance Safety System (BSS)** increases the stability of the **Lex EASyS** by maintaining the ideal center of gravity during the tilt-in-space and recline motions. These extraordinary features also reduce shearing forces on the child's thighs and back during recline. In addition, it ensures that the fixed lateral trunk supports and harness remain in the correct position without the need for repositioning the child or making additional adjustments. The **BSS** makes it easy to maneuver difficult situations such as curbsides, steps, and confined spaces, due to its small and stable wheelbase (that eliminates the need for anti-tippers) and two pivoting casters.

All of the adjustments on the **Lex EASyS** have infinite increments within the range and are accessed using large handled knobs on the base, without the need for additional tools. Growth-accommodating adjustments built into the system extend the back height and seat depth and width. The seating system has plush padding for ultimate comfort.

The durable and lightweight aluminum base adapts so that accessories such as head supports fit securely to the frame. The ergonomically designed height and angle adjustable handrail and footplate offer comfort to both the caregiver and the child.

The **Lex EASyS** seating system comes in a Size 1, for children aged 6 months to 5 years, and Size 2, for the 5 to 12-year age range. With the stroller chassis, caregivers can turn the seating system to be forward or rear facing, and utilize the important therapeutic feature of tilt-in-space. The same seating system (Size 1) transferred to the jogger chassis enables the child and caregiver to participate in outward-bound activities.

The **Lex EASyS** stroller comes equipped standard with accessories including a sun/rain cover, storage basket, headrest, hip guides, shoulder harness, and hip belt. Optional accessories, such as a tray, lateral trunk supports, trunk vests, and abduction blocks are also available. The padded, cotton covers are convenient to remove for machine washing. The lightweight chassis and seating systems total just 37 pounds for the Size 1, 42 pounds for the Size 2, and 39 pounds for the Jogger. Designed for travel, **Lex EASyS** quickly fold up and fit in the trunk of a car.

Last, and by no means least, the **Lex EASyS** strollers passed stringent crash testing requirements and come equipped standard with a 3-point transportation tie down system.

490

We like to think of it as a Ferrari in SUV clothing.

Curbs. Steps. Difficult spaces. Now all quickly and stylishly handled with the LEX EASyS Stroller and it's patented Balance Safety System (BSS®).

Lex EASyS sports an aluminum base, ergonomically designed fit, growth adjustments, and plush padding for ultimate comfort. The incredibly mobile LEX negotiates anything from a city street to a country trail.

Test drive one today. One turn and you'll understand how life in the fast lane is now possible for everyone. Vroom!

Thomashilfen
EASyS BSS
Distributed by

BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #22 or visit www.eparent.com/adinfo

Exceptional Parent Library

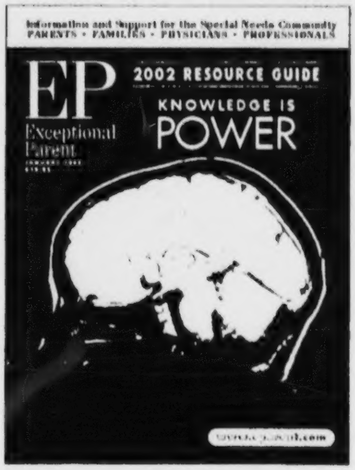
- ☐ Books for Parents, Children and Siblings
- ☐ Books for General Reading and Specific Special Needs
- ☐ Information That You Need: References, Practical Guidance, Coping and Caring.

All selected by the Editors of Exceptional Parent magazine.

FOR A COMPLETE BROCHURE AND DISCOUNT COUPON (GOOD TOWARDS YOUR FIRST PURCHASE)

Order On Line: www.eplibrary.com

or Call: 800-535-1910


Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS
EP
Exceptional Parent
2002 RESOURCE GUIDE
KNOWLEDGE IS
POWER

2002 Annual Resource Guide
Available Through
EP Library $19.95

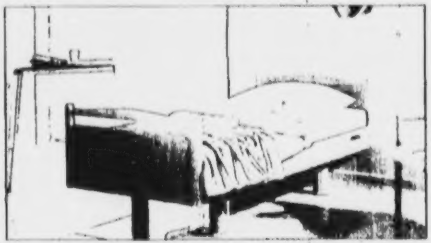
Hertz Supply Co, Inc.

VÖLKER HEALTHCARE BEDS Distributed by Hertz Supply Co Inc

Völker Healthcare Beds address special mobility needs in a unique and positive way. **Völker beds** are different than traditional hospital type beds. They are designed to look like fine furniture, thereby creating a homelike atmosphere in the bedroom. Völker beds are made in high quality wood finishes with special care taken to hide the mechanical devices that can make a bed look clinical. Völker's style of beds has proven very desirable to individuals with disabilities and to families that are providing care for a loved one.

The attractive appearance doesn't mean they are missing any features. Quite to the contrary, they offer more features than most other healthcare beds.

Mobility is provided for in the functions of the **Völker beds.** The head section raises and then also moves a little toward the headboard at the same time. This allows the head section to rise without pushing the feet toward the footboard. This also prevents compression of the individual's mid-section (an important comfort for those who have just had certain types of surgery). The knee section also raises with the additional capability to raise the feet, all activated from the hand control. The bed is height adjustable with the entire bed raising and lowering. This is helpful to assist in entering and exiting the bed as well as providing a welcome assist to the tired back of the caregiver. A reclining chair position can be achieved, allowing for more comfort while eating, working, reading, or watching TV. Side rails are hidden out of sight until they are needed. Disappearing casters on all four wheels allow Völker beds to be moved in any direction. Pushing a button on the hand control electrically operates the casters and brakes.



Décor is always addressed with the **Völker bed.** A variety of head and footboard styles are available in different wood finishes to help match the style of your home. Völker uses beech wood (a hardwood) that is stained to the colors from the current selection. The belletto line from Völker offers a new level of design for those interested in greater style and choice. Beds in the belletto line offer the latest in head and footboard design, and include special mattresses from our beldorma line. *The belletto beds are designed for older youths and adults.* Völker simply offers the greatest choice in healthcare bed design.

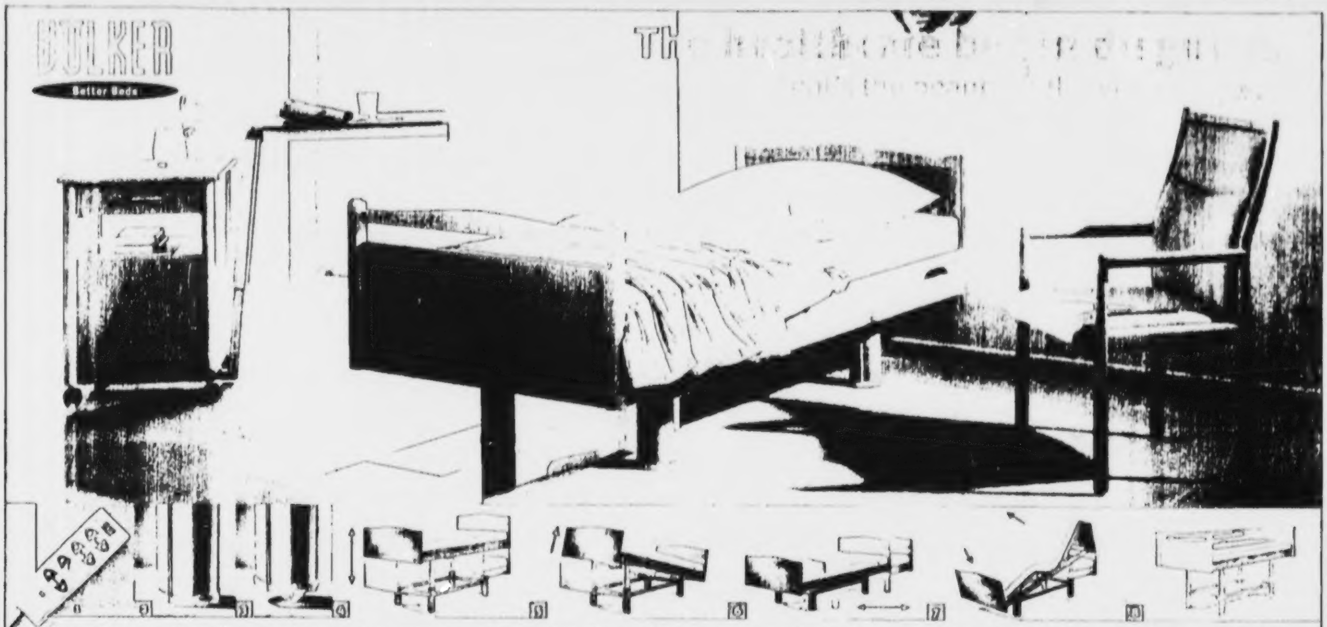
Quality is apparent the minute you lay eyes on a Völker bed. The first thing that is noticed is the aluminum lying surface and other aluminum components under the mattress. It is an impressive sight in a world with so much plastic. The aluminum will not rust or corrode if it comes in contact with fluids. Motors are encased in housings that protect them from fluids and provide a product that is easy to clean. The ease of cleaning the entire bed is made possible by the same design that makes the beds look so nice. The old fashion mechanical components that were so hard to take care of have simply been eliminated. They have been replaced by smooth attractive surfaces that are easy to clean. The hand control is water-resistant with buttons that do not wear out easily. Electrical components remove (plug and unplug) easily so many maintenance tasks can be achieved without the need for expensive technical service. Völker offers a new level of quality for the individual who cannot be bothered by technical difficulties.

Safety is built into all Völker beds. You will be immediately impressed by the fact that a Völker bed will not move away from you while trying to get into or out of it. The large legs with non-slip bottoms hold securely to the floor. Casters are activated only when two buttons (on the hand control) are pushed at the same time, thereby eliminating accidental activation. Any time the bed height is raised, the brakes automatically activate. This helps ensure that the bed is secure to the floor. A special motor system for the lying surface does not use any power unless the hand control button is pushed. This means the occupant in the bed is not subjected to electrical fields 24 hours a day. There is also a multi-step electrical protection system in place to prevent any possibility of electrical malfunction. Of course all **Völker beds** are low voltage for your additional protection and are double insulated to safely work on all household wiring (grounded or non-grounded).

Völker is the complete choice in a healthcare bed.

Please see the adjacent ad for information on how to contact us.

Or—Available from:
Hertz Supply Co Inc
4670 Schantz Rd
Allentown PA 18104
Phone: 800-321-4240
Fax: 610-366-1808
Web: 492



1. Electric operation via a hand control or nurse console (optional). **2.** Absolutely secure braking. **3.** Electric push button casters. **4.** Stable height adjustment 15 1/2–31 1/2" (13 3/4–27 1/2" optional). **5.** Trendelenberg/reverse Trendelenberg (optional). **6.** Easy to move on disappearing casters. **7.** Tilt-in-space positioning that allows for sitting (cardiac) or reclining chair. **8.** Disappearing full lenght side rails.

For more information call 1-800-321-4240

Hertz Supply Co., Inc. · 4670 Schantz Rd., Suite A · Allentown, PA 18104 · www.hertzsupply.com

Hertz SUPPLY

Circle #48 or visit www.eparent.com/adinfo

I am unusual.
I am unstoppable.

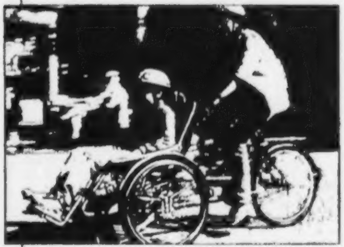
Transforming lives. Thats the power of Easter Seals. Hope Avery was born with a hand and foot abnormality, which led to the amputation of her feet and ankles. But that didnt slower her down. Hope started attending Easter Seals Camps when she was five. There, she learned she could do anything. Even horsebackriding. Easter Seals helped bring Hopes life into full bloom. To learn more, visit www.easter-seals.org

Creating solutions, changing lives.

Easter Seals

BEST COPY AVAILABLE

Frank Mobility



Freedom!

The colorfully designed **DUET** is a wheelchair bicycle tandem that combines the latest in cycle technology with advanced wheelchair design. It's the exhilaration of the wind rushing by your face as friends and family ride together!

Freedom to enjoy the great outdoors like never before! The **DUET** creates recreational opportunities no other product can provide. The **DUET's** "go-anywhere" ruggedness and unique design are appealing to people of all ages and abilities. Everyone wants a ride!

The standard low geared three speed hub enables easy and comfortable pedaling to ensure maximum maneuverability with minimum effort. A seven speed version is also available for more avid bike riders. Both models are available with an electric pedal assist motor. The electric assist works for you when you need it most as you pedal up steep hills and for those extra long rides. Simply turn if off when you desire more exercise!

Safety!

The **DUET** is designed to promote active safety. The easy pneumatic-assisted steering provides light handling while three braking systems ensure complete control at all times. The wheelchair is equipped with drum brakes operated by the bike rider's hand controls. Back pedal brakes are also in place for added braking security. A parking brake provides stability when climbing on and off The **DUET**. The "tricycle" design concept creates a stable ride and when stopping for traffic, there is no need to worry about tipping or trying to balance as the bike sits on all three wheels at the same time.

The wheelchair's low center of gravity provides superior weight distribution and overall stability. This feature also makes it easier for smaller riders to climb aboard! The standard gel seat has an adjustable range of 8 inches and is comfortable for long rides. The **DUET** has been safety tested and has passed US and Canadian government regulations.

Transparent spoke covers and hand shields are available options to keep wandering hands safe from moving spokes and tires.

Quality!

In 1991, The **DUET** was one of three products named "Best New Product of the Year" by North American medical equipment dealers. The award winning ergonomic design of the seat shell provides optimum positioning for the passenger while minimizing surface pressure and reducing the risk of pressure sores. The **DUET** seat supports the back in a natural position and aids in passenger relaxation.

The wheelchair seat upholstery is removable, washable and durable. Velcro strips hold the padding in place.

The headrest can be adjusted up and down, side to side or forward and backward to ensure a comfortable ride for the passenger. The footrest is also adjustable in the same manner, allowing The **DUET** to grow with your child. Swing Away Brackets allow the footrest to swing to either side making it easier for passengers to be seated. For passengers under five feet tall, a Childrens Footboard is available to bring the footrest to their level.

Flexibility!

The **DUET** accommodates "kids" from ages 2 to 95 and all sizes from 20 to 275 pounds! It can be comfortably customized for almost anyone and the quick release coupling system allows you to stop and take part in other activities whenever you want. The wheelchair is easy to use on its own and with the optional push-rims, the wheelchair passenger can move around independently.

The **DUET** can even be ordered without a seat to facilitate customized prescription and special orthopaedic seats, although the majority of **DUET** owners find the standard seat shell comfortable, practical and medically appropriate.

A variety of accessories can be ordered to customize your **DUET** and make the ride more enjoyable for the rider and the passenger from extra safety belts to sun cover and wind protection for the passenger.

Fun!

Riding The **DUET** is beneficial for everyone from mentally or physically challenged to pediatric or geriatric passengers. The sensation of the wind blowing in your face, the thrill of riding in the countryside, down a mountain, or through the city park on such a "neat" machine is therapeutically stimulating to the senses. The cyclist can easily communicate and supervise the wheelchair passenger and get some exercise at the same time!

More and more facilities are adding The **DUET** to their activity program. The **DUET** has been clinically proven to reduce symptoms of depression among nursing home patients when used as part of a specialized biking program. Please contact us for more details regarding this program.

You'll see smiles everywhere you go - everyone wants a ride!

THE DUET
The "Go-Anywhere" Wheelchair/Bicycle Tandem
Enjoy the Great Outdoors like never before!

The DUET is a wheelchair bicycle tandem that allows friends and family to go for a ride in comfort and style. The ergonomic seat is relaxing and allows safe supervision in front. Wheelchair separates for use on its own and for transporting. Hub gear system is easy to pedal. Optional electric motor available.

You'll see smiles everywhere you go - everyone wants a ride!

Frank Mobility Systems, Inc. • Toll Free (888) 426-8581 • www.FrankMobility.com

Circle #38 or visit www.eparent.com/adinfo

NO APOLOGIES FOR RITALIN

No Apologies For Ritalin ○ By Vidya Bhushan Gupta, MD ○ EP8012AD- $19.95

Despite its name, No Apologies for Ritalin is aimed at educating parents of children with ADD by presenting all the treatments available for the disorder.

The first half of the book is a look at what ADD is: the medical aspects, how it is diagnosed, and what causes it. Anecdotes of children diagnosed with the disorder and a discussion of how doctors arrive at their diagnoses begin the book. Issues that parents must deal with, such as understanding and coming to grips with the diagnosis of ADD, whether ADD is a product of bad parenting style, ADD's occurrence with other disorders, and who is most at risk are discussed in this section as well.

Section 2 presents the pros and cons of all treatment options, both conventional and alternative, including non-drug therapies such as psychotherapy and behavior modification. The author, Vidya Bhushan Gupta, MD, MPH, FAAP, writes in his Foreword, "I have discussed the controversy surrounding the use of Ritalin and tried to dispel myths surrounding ADD and Ritalin: 'ADD is not a disease; it is simply a difference of temperament,' 'ADD is due to poor parenting;' 'Ritalin is a mind-altering drug like speed;' 'Don't give Ritalin to your children because they will get hooked on it.'" He explains that his purpose for writing the book is so that "parents of children with ADD will not blame themselves for their child's predicament and will be able to use all the available treatments, including Ritalin, without guilt."

The book offers insights into other issues regarding ADD as well, including: who should treat the disorder and what the goals of that treatment should be; suggestions for parents on dealing with their child's ADD; whether children grow out of their ADD; and how to de-emphasize the negative labels of the disorder by recognizing and building on the strengths of children diagnosed with it.

Patient Persistence

Patient Persistence ○ By Adele M. Gill ○ EP8004GN-$19.95

Patient Persistence celebrates the ability of people to overcome obstacles to achieve their goals. Author Adele Gill invited individuals from every background to tell their stories of "hope, courage, hard work, and endurance related to health, disability, relationships, family, ministry, career, accomplishment and challenge."

Ms. Gill is a certified disability analyst/fellow with the American Board of Disability Analysts, and an advocate of inspirational/motivational self-help. She writes, "Patience and persistence are qualities that are vital to the discovery of our finest, God-given gift; the resilient 'Indelible Human Spirit.' These innate qualities propel people and enable them to do great things and overcome significant hurdles."

Patient Persistence is both motivational and inspirational, offering help and hope to anyone who feels that his or her life is out of control, or that things have gotten so bad that there will never be a way to make it better.

BOTH OF THESE BOOKS ARE AVAILABLE THROUGH THE EP LIBRARY BY CALLING 1-800-535-1910, OR BY VISITING THE WEBSITE AT WWW. EPLIBRARY.COM

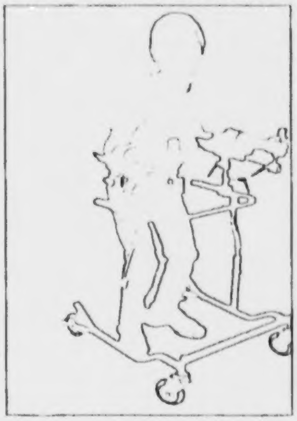
Supporting Your Patients

by Jeffrey Zwiebel, National Sales Manager

Since 1982 Wenzelite Re/hab, located in Brooklyn, New York, has been dedicated to helping patients with special needs. Manufacturers of the original **Adult Safety Roller,** the product line has now grown to include pediatric anterior and posterior safety rollers.

Our pediatric anterior **Safety Rollers** are available in four sizes to accommodate children from early childhood through young adulthood. For the child with a wide gait pattern or one who requires braces to ambulate, we offer a width-expandable model. The **Safety Roller's** adjustments and compatible modular components provide substantial built-in growth. In conjunction with our ingenious automatic braking system and its sturdy and functional design, the **Wenzelite Safety Roller** allows for many years of use.

Many physical therapists prefer posterior (reverse) walkers for children with cerebral palsy and other neurological, orthopedic and developmental disorders. The **Wenzelite posterior Safety Rollers** support users from behind requiring them to procure a more upright posture and to promote trunk extension. Available in three sizes for children ranging from tots to young adults, our **posterior Safety Roller** features one directional wheel that can be disengaged to allow full forward and reverse mobility.



All **Wenzelite Safety Rollers** are height adjustable, fold easily and will stand on their own in the folded position. Naturally, a full line of accessories is available including a superior pelvic stabilizer, adjustable forearm prompts, dial-a-speed tabs for rear wheel resistance and our newest accessory, the posterior positioning bar. This item allows children with shorter arms to be brought forward, enabling them to reach the handgrips. The positioning bar is available only from Wenzelite Re/hab.

Wenzelite Safety Rollers build confidence in children as they encourage safe ambulation and a sense of freedom. The child is never without support and is always in complete control.

In our goal to better serve the physically challenged pediatric patients and to assist their caregivers we have expanded our line even further, to include products that will allow children to achieve the milestones of sitting, standing and mobility. We are dedicated to designing and manufacturing products that will provide maximum support and safety, are aesthetically pleasing to children, parents and caregivers and, most important, are priced correctly for today's market.

Seating is essential to maintain proper body alignment and provide stability and support. Our goal is to combine function with an attractive design. The Wenzelite pediatric seating and positioning systems, the **"MSS Tilt and Recline"** and the **"Cumfi-Sit,"** are designed for children with moderate to severe physical involvement. Their variety of adjustments and positioning options provides maximum support and will accommodate the growing and changing needs of each individual user. Both seating systems are available in two sizes with a choice of a high or low mobility base which converts them from a floor sitter to a high chair. The high base will bring the seating system up to table height. A great accessory to the **MSS Tilt and Recline** is the **"Traveler,"** a lightweight mobility base which will accommodate the seating system. It can retain three tilt positions and all other adjustments. The Traveler features front swivel wheels and oversized rear tires. It folds easily with the seating system in place.

496

Standing is an integral part of most developmentally disabled children's rehabilitation. It helps develop appropriate alignment of the spine, hips, knees and ankles, strengthens muscles and cardiovascular system, improves circulation and range of motion and prevents pressure sores while building endurance. Children unable to bear their own weight can be placed in an upright position and are able to have increased social interaction.

Wenzelite Re/hab manufactures two pediatric standers. The **"Marvel"** freestander is a simple and effective way to provide vertical alignment and upright support. It offers four points of support: at the foot, knee, pelvic and trunk level. The **"Embrace"** meets a variety of positioning needs. It allows prone, supine, and vertical positioning. Positions are easily switched with minimal adjustments for the single user. Both pediatric stander basic models include all accessories.

One of our latest products, the **"First Class"** school chair, was designed for use in the classroom, clinic or home. It is comfortable, attractive and completely adjustable without the need for any tools! It is ideal for physically challenged children with mild to moderate involvement. Its growth capability, height and seat depth adjustability, numerous positioning accessories and available four-wheeled mobility base meet the needs of children as they grow and develop.

Fresh out of the box, our newest product, the **"Dolphin"** pediatric bathing chair, looks like a winner! It is a comfortable and stable adjustable bathing chair that fits all standard tubs. Included with the basic chair is an adjustable headrest, lap belt and a trunk support. The back support has 10 tilt positions including trendelenberg. The seat has 5 tilt positions and can adjust for depth. The **"Dolphin"** folds flat and weighs only 6.5 pounds.

And finally, soon to be announced, the **Wenzelite Gait Trainer** will be making its long awaited debut. Stay tuned!!

In our ongoing effort to interact with doctors, therapists, and you the parent, we offer the following services:

Product Evaluations
Custom Product Modifications
Direct Drop Shipments
Customer Service Assistance

For those of you with access to the internet we invite you to visit our website, www.wenzelite.com. If you need immediate assistance, please call our toll free number, (800)706-9255. We look forward to your feedback. Let's join hands in supporting your children!

WenzeliteRe/hab

Providers of

Pediatric Rehab Equipment

SEATING SYSTEMS

BATHING CHAIRS

STROLLERS • STANDERS

WALKERS

CALL US AT

718-768-8002 / (800) 706-9255

For information about our **FREE EVALUATION PROGRAM**

www.wenzelite.com • e-mail: wenzelite@aol.com

Circle #82 or visit www.eparent.com/adinfo

THE ACCESSIBILITY SHOW

THE ONLY SHOW OF ITS KIND

between New Jersey and Florida!

The Accessibility Show features Manufacturers of Adaptive Equipment, Assistive Products and Devices. Service Related Companies and Special Needs Organizations will be on hand to provide valuable information.

★ **Accessible Vans and Conversions**
★ **Adaptive Computers & Software**
★ **Assistive Products and Devices**
★ **Home and Vehicle Lifts**
★ **Wheelchairs for Children and Adults**
★ **Augmentative Communication Devices**

York Expo Center • York, PA

Friday, May 3, 2002 (12:00 P.M. - 8:00 P.M.)
Saturday, May 4, 2002 (10:00 A.M. - 5:00 P.M.)

Visit Our Website For A FREE ADMISSION COUPON and Directions

www.TheAccessibilityShow.com

R.E.A.L. Design Inc.

R.E.A.L. Design (Rehab and Educational Aids for Living) is a small business located in the foothills of the Adirondacks in upstate New York. The company researches, designs and manufactures products for children with neuromuscular disorders including cerebral palsy and spina bifida. Co-owners Sam Camardello, a mechanical engineer and Kris Wohnsen, an industrial designer, started their company in 1994 in Kris' basement. Before starting R.E.A.L. Design, the two were employed in product development for Tumble Forms. They were part of a team that developed a variety of adaptive equipment including the Tadpole Infant Positioning SystemTM, the Ready RacerTM and the TristanderTM. Over the past years they have been the recipients of design awards from the National Society of Industrial Designers for their children's products and a design grant from the National Endowment for the Arts. Today R.E.A.L. Design has grown to several employees and a much larger facility with the capability of fabricating wood, metal, and plastic components for their products. The staff of dedicated people from college students to "ex-retirees" is committed to making equipment of the highest quality.

REAL Design's focus is on innovation and so as a design driven company they believe in working closely with therapists, parents and other caregivers in all phases of development from concept prototype to final production. "By actively seeking the involvement of clinicians and parents, educators and therapists it helps us understand first hand the needs of children" says Kris Wohnsen. "The decision as to what products we develop is based upon the advice of people whose input we feel is the reason for the success of our product line . " In making products that would assist children R.E.A.L. Design hopes to consider all the child's needs including not only their physical abilities but designs that will enhance their social and emotional growth as well. The company feels strongly that rehab products for children will be enhanced with a creative and aesthetic quality not usually associated with adaptive technology. Seating systems made up of grey leather strapping, metal poles and large black knobs can appear intimidating. It is the philosophy of R.E.A.L. Design to develop products that are not only functional and well constructed but also playful as well. If play is the 'work" of children than products designed for children should address those needs. Bright colors, rounded contours, and playful shapes make a product fun to use and have around. Sisters, brothers or other school children often join in to play during therapy exercises with our products which is precisely the kind of social interaction parents want for their disabled child.

Some of their current product line include:

The LadyBug Corner Chair which is designed for pre-school children. The little red chair with the "ladybug spots" is designed to allow children to sit in either long leg or conventional sitting by simply adjusting the seat back .

The High-Low Chair, a height adjustable chair which (when detached from its pedestal base) becomes a mobil floor sitter.

The Convert-Able Table which adjusts in height from 21 - 37" from the floor so it can be used by children in wheelchairs, standing frames and gait trainers in home school or therapy setting. The table can adapt to become a computer desk, an art easel and even a sensory stim bowl (for holding liquids) by simply interchanging the tops which snap on and off easily.

The Updown Chair, designed for school age children has a foot operated seat height adjustment which can be changed from 12" to 27" from the floor.

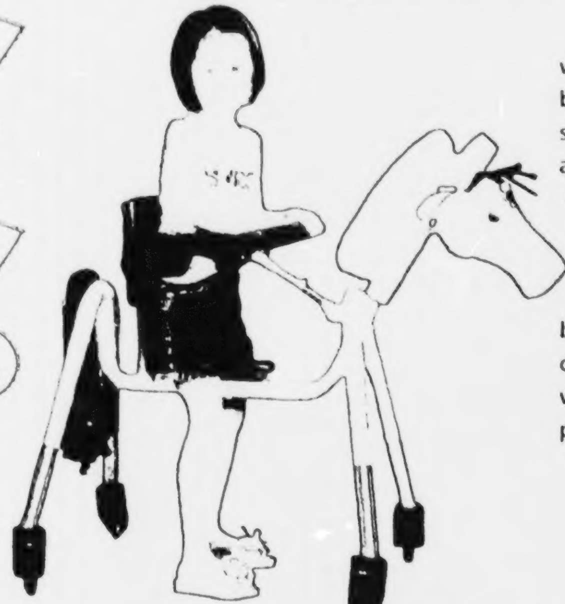
Vivo, the newest product from R.E.A.L. Design is a combination balance rocker and gait trainer. Vivo is designed to address the positioning requirements of the young child ages six months to three years. His bouncy head and colorful beaded mane and tale are part of his appeal for young children. Through working with early intervention therapists it was determined there was a need to design a mobility product for the very young child learning to walk that would take into consideration their need for play .

The future of the company includes continuing to develop innovative products that address the needs of children and the therapists who work with them. As a small company R.E.A.L. Design has the freedom to explore concepts and ideas

R.E.A.L. Design Introduces VIVO™

The New Balance Rocker and Gait Trainer in One!

V
I
V
O



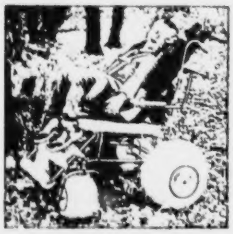
Children will love VIVO, the playful, spirited little pony with the head that bounces when moved and a colorful beaded tail. Parents and therapists will appreciate the valuable skills children gain by playing on VIVO because it functions as a balance rocker or gait trainer by simply interchanging the legs which snap on and off easily. As a rocking horse, VIVO promotes balance reaction skills and upper body postural development. As a gait trainer, it provides incentive for a child to learn ambulation skills. The soft upholstered seat back, with molded laterals, is height adjustable to position children comfortably and securely for rocking or learning to walk. Accessories are available for adapting VIVO to a child's positioning needs.

R.E.A.L. DESIGN
1.800.696.7041 Fax: 1.315.429.3071
www.realdesigninc.com

Circle #67 or visit www.eparent.com/adinfo

Natural Access®

All-Terrain Wheelchairs for Beaches and Parks!



For more information or to order please call...
1-800-411-7789
www.landeez.com

Circle #31 or visit www.eparent.com/adinfo

Personalized Interdisciplinary Programs

HMS School for Children with Cerebral Palsy serves children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

Physical & Occupational Therapies
Special Education
Speech/Language Therapy
Music Therapy
Communication Aids
Special Medical Attention
Adapted Recreational Activities

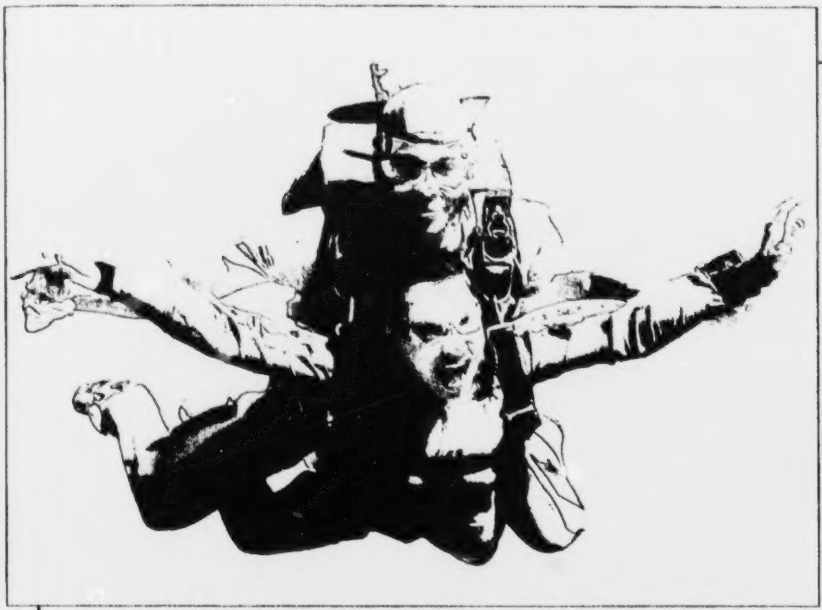
Computer Technology
Communication Devices
Environmental Control
Powered Mobility

HMS, founded in 1882, is open to students two to 21 years. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy
4400 Baltimore Ave, Philadelphia, PA 19104
(215)222-2566

Circle #49 or visit www.eparent.com/adinfo



Southern California Moms "Jump" at the Chance to Help Kids with Disabilities

On Saturday, May 11—Mother's Day weekend—a group of ordinary, relatively sane people will parachute out of an airplane at 13,000 feet in order to raise money—and heart rates—for PAUSE4KIDS, a Ventura County-based nonprofit organization that helps children with physical and developmental disabilities.

The event, "WE CAN FLY," was conceived by Keri Bowers and Terri Mandell, community activists, mothers of children with special needs, and recently converted skydiving enthusiasts. After a mutual friend informed them that she'd done a tandem skydive for her fiftieth birthday, the two Southern California moms decided to take a dive for their cause and invite others to join them. While experienced skydivers will be participating, the majority of participants will be people like Keri and Terri, who are novices at skydiving, but, as parents, teachers, friends and supporters, are experts at caring for children with special needs.

Keri Bowers, whose 13-year-old son, Taylor, has autism, is the founder of PAUSE4KIDS and a cofounder of WE CAN FLY. "It's difficult to explain the link between skydiving and raising a child with special needs," says Keri, "but it definitely has to do with fear and risk-taking. Caring for a child with special needs can be a terrifying experience. Jumping out of an airplane pales in comparison."

Terri Mandell, co-creator of the event, has an 11-year-old son with a life-threatening illness. She also finds skydiving to have a profound emotional benefit. "When you have a seriously ill child, facing fear is all in a day's work. Falling through the sky is a relief compared to the things I experience on an average day."

PAUSE4KIDS works closely with teachers, social agencies, therapists and parents to improve special education programs through organized advocacy. In addition to pushing for legislative reform, PAUSE4KIDS also develops social and recreational opportunities for children with special needs according to its philosophy that special education must encompass education of the whole child.

WE CAN FLY will raise funds by asking donors either to sponsor an individual skydiver or to make a tax-deductible contribution directly to PAUSE4KIDS. The event will take place on Saturday, May 11 at Skydive Perris, the largest skydiving facility in North America. Sponsors, spectators and skydivers (beginners to advanced) are all invited. Admission for spectators is free and special rates are being offered to skydivers.

Skydive Perris, 90 miles southeast of Los Angeles, California, has a large picnic and camping area, a swimming pool, and a restaurant/bar with a view of the drop zone. Visit their Web site, www.skydiveperris.com, or call (800)-SKYDIVE for driving directions and information.

For more information, contact PAUSE4KIDS 50 West Hillcrest Drive, Suite 211 • Thousand Oaks, CA 91360 at (805) 376-2918 or visit the WE CAN FLY web site at http://www.wecanfly.org. EP

Sharon Costello, Keri Bowers and Terri Mandell

Northern New Jersey
Maternal Child
Health Consortium

THE NORTHERN NEW JERSEY MATERNAL CHILD HEALTH CONSORTIUM PRESENTS
REGIONAL EDUCATION SPRING CONFERENCE 2002

Attention Deficit/Hyperactivity Disorder: Maximizing Potential
Friday, May 17, 2002
8:00 am - 4:30 pm
Woodcliff Lake Hilton
Woodcliff Lake, New Jersey

SPEAKERS:

Pasquale Accardo, MD, FAAP
Professor of Pediatrics, New York Medical College
Director, Child Development Services, Westchester Institute of Human Development

Arthur Shapiro, EdD
Professor of Special Education, Kean University

Grace S. Lee, RN, MSN, SNP
Nurse, Frelinghuysen Middle School

Vidya Gupta, MD
Clinical Associate Professor of Pediatrics, New York Medical College Director, Developmental Pediatrics, Metropolitan Hospital Ctr, New York, NY

Bruce N. Miller, PhD
Vice President, Central Region Youth Consultation Service

Brenda Marshall, MS, EdD, CHES
Professor of Health Education
City University of New York

Joseph M. Valenzano, Jr. MBA, CMA, APC
President, CEO & Publisher, EXCEPTIONAL PARENT Magazine

Maryann Dobbin
Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD)

TOPICS

1. Positive aspects of ADHD.
2. Behavioral intervention strategies for children with ADHD in the home and school environments.
3. ADHD and related conditions.
4. Observable behaviors in early childhood that are suggestive of ADHD.
5. Potential co-morbidities seen in adolescents with ADHD.
6. Risk of substance abuse in adolescents with ADHD.
7. Personal and parental perspectives of ADHD.
8. Resources for support, education, and advocacy.

TARGET AUDIENCE

Those who work with children and adolescents with attention deficit/hyperactivity disorder, including pediatricians, neurologists, family practitioners, psychologists, psychiatrists, nurses, social workers, counselors, teachers, parents, and others with an interest in supporting children with attention deficit/hyperactivity disorder.

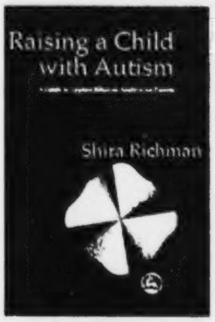
FEES

$50 PARENTS
$90 NORTHERN NJ MATERNAL/CHILD HEALTH CONSORTIUM HOSPITAL STAFF AND GENERAL MEMBERS
$100 OTHER PROFESSIONALS

For more information, call (201) 843-7400
Or email: info@nnjm-chc.org

"Raising a Child with Autism"

Reviewed by Marianne Taylor



Raising a Child with Autism: A Guide to Applied Behavior Analysis for Parents

by Shira Richman
Jessica Kingsley Publishers
London, Philadelphia
Available from the EP Library,
(800) 535-1910
code: TF9106AT
price: $19.95
pages: 173, paperback

Is it possible to learn behavior modification from a book? Suspending my skeptical response, I will consider how this book might assist someone in learning what I call the art of "technical parenting." This is the art and skill of parenting a child who may pose extraordinary challenges such as aggression, spitting, lack of cooperation or other difficulties well known to some parents of children with disabilities.

Readers who believe they can learn behavior modification from a book are advised to skip directly to Chapter 4 for a greater likelihood of success. Chapters 1 through 3 are devoted to the "developmental theory" approach to life, the somewhat pedantic and highly technical version of learning theory and behavior analysis.

Generally speaking, "developmental theory" states that A must precede B so that C can occur. This theory makes sense until you apply it to the lives of real people. When you look at its application to children and adults who have disabilities, then it goes something like this: Johnny cannot possibly be included in regular classes until he learns to [fill in the blank: talk, walk, use a communication board or use the bathroom on his own]. In Chapter 1, the author fills this "blank" with "years of therapy" not specifying which kind, as a necessary prerequisite. She states that "Some [children with autism] who begin therapy at a very young age are even integrated into regular school classes." Families and children with disabilities already encounter too many uninformed "dream stealers" who can always find a reason why "inclusion" is not possible — they don't have to hear it from our own "experts"!

In a quiet protest of Chapter 3, I want to tell the story of a boy with autism. He was very popular in his integrated eighth grade classroom because he knew the town's phonebook listings by heart, all because of his amazing memory. He could recite a phone number or a name when given an address and vice versa. The kids thought that this was very cool; and they were right!

These children could appreciate him for who he was and saw his special gift. They were willing to help him with other things that he had difficulty doing because he was a classmate and a friend. That is because, except in the alphabet, A does not always precede B. Often this different sequence exists in our language to make unique and beautiful words, which are quite out of alphabetical order!

This book improves in later chapters as the author brings to bear her broad and deep understanding of how to help children with autism and their families. Chapter 4 provides a wealth of practical information and approaches to solve dilemmas common to these families. For parents, knowing that others share similar experiences and that they are not alone in facing the behavioral problems associated with autism is a gift for the spirit. Learning the proven strategies for resolving these problems is a tool for life; this book offers something for the exceptional parent's toolbox.

The chapter on sibling interaction, while short, is very useful. The author has personal experience both as the sister of someone with a severe cognitive disability who lived at home and as the mother of a child with Asperger's syndrome. It is clear to me that her advice on supporting siblings is on target, sensitive and conveyed with a warmth that does not radiate in earlier chapters.

The final chapter provides some insight into managing the occasional thoughtless or hurtful comments about your child or your parenting made by others in public situations. Sound familiar? The advice here is sound but somewhat limited. I would add to it and advise parents to use the help of friends, therapists and other supportive professionals in building and preserving the sense of well-being and self-assurance from which springs the joy, energy and courage to understand that A does not always precede B. **EP**

Marianne Taylor is the Senior Project Director at the Human Services Institute, an NADSP (National Alliance for Direct Support Professionals) co-chair and mother of a son with special needs.

The National Academy of Sciences has issued a report on educational interventions for young children with autism. The report, "Educating Children with Autism," published by the National Academy Press, is available online at www.nap.edu/catalog/10017.html.

National Alliance for Autism Research

Committed to Accelerating Biomedical Autism Research to Unlock the Mysteries of Autism Spectrum Disorders

The National Alliance for Autism Research (NAAR) is the first national nonprofit organization dedicated to funding and accelerating biomedical research and scientific approaches that seek to determine the causes of, find treatment for and ultimately discover a cure for autism spectrum disorders.

Established in 1994, the National Alliance for Autism Research has committed more than $6 million in grants to fund more than 80 autism research projects worldwide. This year, the National Alliance for Autism Research will invest millions more to fund dozens of additional research projects and mentoring fellowships.

The driving force behind the creation of the National Alliance for Autism Research, Karen and Eric London, started the organization a few years after their son, Zachary, was diagnosed with autism.

As the Londons became immersed in learning all they could about autism and working with their son, they became increasingly aware of the dearth of serious research on autism spectrum disorders. Frustrated, Karen began to think of how they could make a difference.

A corporate attorney by training, Karen began to investigate the nation's leading disease-specific

continued on page 109

NAAR co-founder Karen London and her inspiration, son Zachary.

What is Autism?

Typically diagnosed by the time a child reaches age 2 to 4, autism is a complex brain disorder that often inhibits a person's ability to communicate, respond to surroundings or form relationships with others. The disorder was first identified by Dr. Leo Kanner more than 50 years ago and is considered a spectrum disorder because symptoms and severity vary from individual to individual.

The causes of autism are not known.

Physicians have no blood test or diagnostic scan to rely on in diagnosing autism. Currently, the diagnosis of autism is based solely on the observation of behavior based on a constellation of impairments in communication, social, play and other skills.

There are no specific medical treatments for autism.

The only "treatment" strategies for autism are based on behavior and education and are designed to help a person with autism lead the fullest life possible. Some individuals with autism benefit from pharmacological treatments.

There is no cure for autism.

Although some individuals on the autism spectrum are mildly affected, typically, autism is lifelong.

Common Facts About Autism:

- Autism affects children of all racial, ethnic and socioeconomic backgrounds. The National Institutes of Health estimates that it occurs in as many as one in every 500 children. Some recent estimates of autism's prevalence are even higher.
- There are currently more than 500,000 people in the U.S. with some form of autism, making it the third most common developmental disability, after cerebral palsy and mental retardation.
- Symptoms of autism often don't appear until the child is between the age of 1 or 2 years.
- Autism is four times more prevalent in boys than in girls.
- Despite a national interest in autism and a high prevalence in children, autism research remains one of the lowest funded areas of research by both private and public sources.

Research

The National Alliance for Autism Research has funded some of the most exciting advances in autism research conducted at top universities, medical centers and research institutions. Recent projects funded by the National Alliance for Autism Research include:

Baby Sibling Study

This multi-site study is designed to identify early signs of autism and to determine whether early interventions can improve the quality of life for children with autism and their families.

Researchers in the U.S. and Canada are evaluating a large number of children at an increased risk for developing the disorder—the infant siblings of children diagnosed with autism. While there is currently a trend toward earlier diagnosis, most children are not diagnosed with autism until they are 2 to 4 years old. Babies involved in this study will typically be between 3 and 6-months-old—which will enable scientists to study children far younger than ever before and follow them prospectively for the first signs of delayed or abnormal development.

Autism Tissue Program

In 1998, the National Alliance for Autism Research played an instrumental role in establishing the Autism Tissue Program, the first parent-led brain tissue donation program for autism research. The program currently has enrolled more than 2,600 tissue donors.

The Autism Tissue Program makes post-mortem brain tissue available to as many qualified scientists as possible to advance autism research. Using brain tissue, scientists can go far beyond the limits of other technologies to study autism on a cellular and molecular level. Brain tissue studies also increase the ability to diagnose autism earlier and to assess better the risks of inheritance.

The program is a collaborative effort with the Autism Society of America Foundation and the Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute at the University of California Davis. For information about tissue donation, call (877) 333-0999.

Genetics

Genetics has been an area of research funded by the National Alliance for Autism Research since NAAR first began awarding grants and remains an area of intense focus because of autism's apparent hereditability. Comprehensive studies of identical twins and siblings have determined that some individuals are genetically susceptible to autism. The twin studies determined that in two-thirds of identical twins where one twin develops autism, the other twin will also develop autism. Additional studies have determined that siblings of children diagnosed with the disorder are between five and 10 percent more likely to develop the disorder.

Recent genetics projects funded by the National Alliance for Autism Research include the annual Calloway Gardens Genetics Collaborative, an annual retreat co-sponsored by NAAR and the Nancy Lurie Marks Family Foundation that provides a unique venue for the world's top research teams to teams to share findings and combine data with the hope of accelerating the identification of autism susceptibility genes; and the development of the Web site, http://www.exploringautism.org, an online educational tool for parents that explains the genetics of autism and provides current news about genetics research and autism. This Web site—funded by NAAR—was created by the Center for Human Genetics at Duke University Medical Center and Tufts University/New England Medical Center.

MMR & Autism

Perhaps no topic related to autism is as controversial as the debate surrounding the MMR (measles, mumps, rubella) vaccine. Some parents and family members of children with autism believe the MMR vaccine caused their child's autism. Parents report that their children were developing normally until they received the MMR vaccine, after which the children started showing signs of autism.

At the request of the Centers for Disease Control and Prevention and the National Institutes of Health, the Institute of Medicine at the National Academy of Sciences conducted a review in 2000 of all the evidence related to the MMR vaccine and autism. The same year, the American Academy of Pediatrics independently reviewed the topic of the MMR vaccine and autism. Both studies concluded that the research to date does not support a link between autism and the MMR vaccine. Nonetheless, both reports called for more research into the relationship between MMR and autism.

In 2001, the National Alliance for Autism Research and the Centers for Disease Control and Prevention provided the funding for an autism component to a large-scale research project in Denmark called the Danish National Birth Cohort, which will involve 100,000 pregnant women and then their newborns. The autism component of this study will specifically evaluate the effects of the MMR vaccine and autism.

WALK·F.A.R.

WALK F.A.R. FOR NAAR

Established in 2000, Walk F.A.R. for NAAR has become the National Alliance for Autism Research's signature fundraising and autism awareness event held annually in numerous communities across the United States. Since the first Walk—founded by NAAR volunteers Renee Georgi and Joan Stahl in Pittsburgh—more than 20,000 walkers have participated in the event, which has raised more than $5 million for autism research.

The success of the Walk is a testament to the network of families, volunteers and supporters that the National Alliance for Autism Research is fortunate to have in cities and towns throughout the country.

2002 WALK F.A.R. for NAAR Schedule

Pittsburgh
Saturday, May 18
Pie Traynor Field at
North Park, Pittsburgh, PA
(412) 487-6851

Westchester/Fairfield
Sunday, June 2
Manhattanville College,
Purchase, NY
(203) 964-9880

Southern New Jersey
Saturday, June 8
Cooper River Park,
Pennsauken, NJ
(888) 777-NAAR

Seattle
Sunday, June 9
Marymoor Park,
Redmond, WA
(206) 275-4490

Iowa
Saturday, June 15
Gray's Lake, Des Moines, IA
(515) 246-7940

Long Island
Saturday, Sept. 28,
Eisenhower Park,
East Meadow, NY
(516) 327-4646

Buffalo
Sunday, Sept. 29
Delaware Park, Buffalo, NY
(716) 522-9185

New England
Sunday, Sept. 29
MDC Artesani Park,
Brighton, MA
(978) 887-6966

Central New Jersey
Sunday, Oct. 6
Mercer County Park,
West Windsor, NJ
(888) 777-NAAR

Northern New Jersey
Fall 2002 - Date not yet determined
Giants Stadium, East Rutherford, NJ
For more information, call (888) 777-NAAR

Miami/Dade County
Saturday, Oct. 26
Crandon Park,
Key Biscayne, FL
(800) 610-NAAR

Broward County
Sunday, Nov. 10,
C.B. Smith Park,
Pembroke Pines, FL
(800) 610-NAAR

West Palm Beach
Sunday, November 17
John Prince Park,
Lake Worth, FL
(800) 610-NAAR

WALK F.A.R. for NAAR is also scheduled to return to the following cities in Spring 2003:

- Washington, D.C.
- Rochester, NY
- Los Angeles, CA

For more information on any WALK events or about starting a WALK event in your community, call (888) 777-NAAR.

Discover
New England Village, Inc.

"A community rich with opportunity, sharing and growth"

Established as a non-profit corporation in 1972, New England Village is a warm, caring stable and secure environment where young adults with mental retardation can lead a high quality lifestyle with opportunities for growth and friendship.

Our campus, set on 80 beautifully wooded acres just 25 miles south of Boston, offers attractive contemporary style homes and townhouse apartments. Learn about our full range of residential options, extensive vocational and education programs, and wide spectrum of recreation and social opportunities. We invite you to meet our dedicated and caring staff and speak to other families about our village.

Call (781) 293-5461, or write Judy Andracchio, Admissions Coordinator, to arrange your personal visit or request our brochure. We invite private and state-sponsored referrals.

New England Village, Inc.
664E School Street • Pembroke, MA 02359
781- 293-5461 • website: newenglandvillage.org
email: info@newenglandvillage.org

30L-B
30M-B
TWO great styles to choose from!
Model 20
Model 350
Pediatric Shower/Commode Chair

THE Adjustable Bath Chair
by DURALIFE

- 9" leg extensions available.
- Adjusts to multiple positions for individualized comfort.
- Safe, quick push-button adjustment mechanism located out of child's reach.
- Highly-durable, comfortable mesh fabric is easy to clean and dries fast.
- Safety straps included for those who require extra support.

DURALIFE, INC.
Call Toll Free: 1-800-443-5433
Fax: 570-323-9762
E-mail: duralfe@aol.com
Website: www.duralife-usa.com

Circle #33 or visit www.eparent.com/adinfo

Getting information from EP advertisers is MUCH FASTER ONLINE!

It's as easy as a click of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers

CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in EXCEPTIONAL PARENT

How to use this service

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature
3. Fill in your name and address on the card and mail the postage paid card. You will receive free literature from each company for which you circled a number
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly

Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
21	ADAPTIVEMALL.COM	44
7	ALTIMATE MEDICAL	85
18	ANNANDALE VILLAGE	8
20	ASSISTIVE TECHNOLOGY, INC	55
22	BODYPOINT DESIGNS, INC	91
24	CAMPHILL SPECIAL SCHOOL	62
25	CHARLES C THOMAS	4
26	COLUMBIA MEDICAL	73
27	CONNETQUOT WEST	46
28	CONVAID	77
29	CROTCHED MOUNTAIN REHAB	118
30	CYBERONICS, INC	40-41
31	CYCLETOTE CORP	89
32	DRIVE MASTERS	46
33	DURALIFE, INC	105
34	EDEN FOODS, INC	7
200	EP LIBRARY PAGES	110-111
50	EP NEWBORN SCREENING DVD	58-59
199	EP SUBSCRIPTION PAGE	17
35	EQUIPMENT SHOP	123
36	EVERGREEN CENTER	56
37	FORD MOBILITY	C3
38	FRANK MOBILITY	95
39	FREEDOM CONCEPTS	65
40	FREEDOM DESIGN	75
41	FREEDOM MOTORS USA	63
42	GLOBAL POWER SYSTEMS INC	37
43	GULDMANN, INC	64
44	H.D.I.S	53
45	HANDICAPS, INC	62
46	HARD MANUFACTURING	16
47	HAVERICH ORTHO-SPORT, INC	37
19	HEARTSPRING	23
48	HERTZ SUPPLY CO., INC	93
49	HMS SCHOOL	99
	HOUSE AD	106
51	HOUSE AD	119
52	INNOVATIVE PRODUCTS	64
53	KENNEDY KRIEGER	39
54	LAWYERS, INC	33
55	LIBERTY MOTOR COMPANY INC	9
56	LITIGATORS, INC	19
57	MARCH OF DIMES	25
58	MEDTRONIC NEUROLOGICALS, INC	C2
59	MELMARK	31
60	MERRILL LYNCH	43
61	MOBILITY RESEARCH	53
31	NATURAL ACCESS	99
	NEW ENGLAND VILLAGE	105
62	NEW HARBINGER PUBLICATIONS	56
63	OCEAN HYPERBARIC CENTER	117
64	OTTO BOCK	81
65	PERMOBIL	71
66	PRIDE MOBILITY	83
67	REAL DESIGN	99
68	RED BARN ENTERPRISES	24
69	ROSS LABORATORIES	11
70	SAMMONS-PRESTON	79
71	SIGMA TAU	1-2
72	SNUG SEAT INC	13
73	SOUTH FLORIDA CNTR FOR HOPE	109
74	STEWART HOME SCHOOL	109
75	SURE HANDS INTERNATIONAL	32
76	THE BABY JOGGER COMPANY	87
77	THE NYU HOSP FOR JOINT DIS CTR	57
78	TORONTO HYPERBARIC INC	45
79	ULTRAFLEX SYSTEMS, INC	32
	UMDF	15
80	VAIL PRODUCTS	C4
81	VERIZON	3
82	WENZELITE MEDICAL SUPPLY	97
83	WOODBURY PRODUCTS	44
84	WORLD CONGRESS	48-51

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged.
The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

continued from page 108

nonprofit groups and consider whether autism would benefit from a similar organization. She became more active in local autism organizations and began attending conferences, raising questions about the lack of autism research in the country.

Eric, a psychiatrist who had spent several years engaged in brain research, had also noticed his growing caseload of patients with autism. The Londons discussed the idea of forming an autism organization with pioneering autism researcher Dr. Margaret Bauman, who enthusiastically endorsed the idea.

The family's basement became NAAR's first office. Work was completed during the day, with the children at school, and in the evenings, after the children were asleep.

Karen and Eric persuaded 22 leaders from the nation's top universities and research centers to form the group's first Scientific Advisory Board. Karen also assembled a board of trustees by asking doctors, journalists, professors and Philadelphia Eagles owner Jeffrey Lurie to help guide the young organization. At the same time, she started to form an Honorary Board to lend their talents and resources to raising funds and awareness for autism research. Honorary board members include the likes of musicians and composers Wynton Marsalis and Branford Marsalis, actors Joe Mantegna and Aidan Quinn, and football legends Dan Marino and Doug Flutie. Most members of the board and honorary board have a family member with autism. EP

Funding Autism Research

NAAR awarded its first research grants in 1997. Since then, its continuous funding of pilot studies and collaborative research projects have played a key role in the increased funding for autism research allocated by the National Institutes of Health. The WALK F.A.R. for NAAR autism walkathons continue to spread awareness about the need for more autism research in communities across the country. (See sidebar for more information.)

The National Alliance for Autism Research was created in a spirit of optimism and excitement over the opportunities for promising research in autism. Its mission includes providing grants to researchers for new pilot studies, mentoring fellowships to recruit new researchers to focus on autism, and funding larger, collaborative research projects that have the potential to yield major scientific advances in autism research and scientific conferences. Autism studies funded by the National Alliance for Autism Research cover a wide range of areas, including:

- Genetics
- Immunology
- Epidemiological studies
- Cognition
- Molecular & Cell Biology
- Neuroanatomy & Neuroimaging
- Language & Communication
- Behavior

For more information contact NAAR at:
National Alliance for Autism Research
99 Wall Street • Research Park • Princeton, NJ 08540
(888) 777-NAAR • naar@naar.org • www.naar.org

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #74 or visit www.eparent.com/adinfo

Hyperbaric Oxygen Therapy [HBOT] is the breathing of 100% oxygen under increased atmospheric pressure. The effects of HBOT on the organs and tissues of the body are multi faceted.*

South Florida Center for H.O.P.E. offers a clean and bright friendly atmosphere, using only state-of-the-art equipment. Our doctors and technicians are trained by a UHMS accredited course and certified in HBOT by the NBDHMT. They come with many years experience in the field of hyperbaric medicine.

* Hyperbaric Medicine Practice
Eric P. Kindwall, M.D.

WE OFFER H.O.P.E.
[HYPERBARIC OXYGEN PRODUCING ENVIRONMENT]

CONDITIONS TREATED WITH HBOT
CEREBRAL PALSY [CP]
TRAUMATIC BRAIN INJURY
ANOXIC ISCHEMIC ENCEPHALOPATHY (AIE)
NEAR DROWNING
STROKE [CVA]
MULTIPLE SCLEROSIS [MS]
NON-HEALING WOUNDS*
RADIATION INJURY*
AUTISM
* CURRENTLY APPROVED BY FDA

ANCILLARY SERVICES
INTEGRATED MANUAL THERAPY
PHYSICAL THERAPY
OCCUPATIONAL THERAPY
SPEECH THERAPY
BIO RESONANCE THERAPY
NEURO-BIOFEEDBACK

South Florida Center for H.O.P.E
1898 H West Hillsboro Blvd.
Deerfield Beach, FL 33442
[954] 571-9392
Toll Free: [866] 473-HOPE

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #73 or visit www.eparent.com/adinfo

WWW.EPLIBRARY.COM

EP LIBRARY

Exceptional Parent

THE SPECIAL NEEDS BOOKSTORE

FOR YOUNG PEOPLE

Ben King Of The River
David Gifaldi with illustrations by Layne Johnson

The touching story of Ben, a young child with a developmental disability, and his brother who encounter some different and exciting situations and people on a family camping trip.

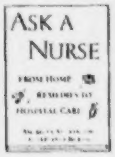
AW6354YP **$14.95**

Nursery Rhymes from Mother Goose
Told in Signed English
Harry Bornstein and Karen L. Saulnier; Illustrated by Patricia Peters and Linda Tom

More than a dozen favorite rhymes illustrated with full color paintings accompanied by 389 drawings showing verses in Signed English. Designed to help young readers strengthen their language skills

GU1086YP **$14.95**

HEALTHCARE



Ask A Nurse
From Home Remedies to Hospital Care
American Association of Colleges of Nursing
Edited by: Geraldine Bednash, Ph.D., R.N., FAAN

This book provides comprehensive information on standard treatments, home remedies, and effective over-the-counter medications for health problems ranging from allergies to yeast infections. With the expertise of 550 nursing schools and personal advice from 100 registered nurses nationwide, you can learn what to do whey your or a family member is sick and in need of care. Chapters are arranged alphabetically so it is easy to find what you need

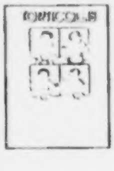
SS6875CN **$30.00**

Transcultural Aspects of Perinatal Health Care
A Resource Guide
National Perinatal Association

This book, revised in March 2002, offers resources and information supporting requirements of the Office of Civil Rights, the Maternal and Child Health Bureau of HRSA, and JCAHO in Cultural Sensitivity, Cultural Competency, Core Health Status Indicators, Developmental Health Status Indicators, Interpreter Competency and Patient Education. A great source for Title V Applications. User Friendly chapters, fourteen (14) so far, include narrative and support sections. Easy to include updates as they become available.

EP8020PH **$79.00**
EP8021PH (March, 2002 Update) **$19.95**

PHYSICAL DISABILITY



Torticollis
Differential Diagnosis, Assessment and Treatment, Surgical Management and Bracing
Karen Karmel-Ross, PT, PCS, LMT

Clearly reflects the philosophy of the team approach by including contributions from a pediatric orthopedist, pediatric general surgeons and several pediatric physical therapists. Reviews the differential diagnosis and surgical management of CMT and provides a detailed, comprehensive approach to the nonoperative management of CMT by bringing together a wide range of related materials under one cover.

KP3171DS **$24.95**

Easy for You to Say
Miriam Kaufman, MD
Q & As for Teens Living With Chronic Illness or Disability

This book addresses issues faced by teens and young adults with disabilities and chronic conditions. The information is presented in a straightforward questions and answer format that can easily be browsed through, rather than read cover to cover. Divided into eight chapters to enable the reader to jump to a topic of interest such as Doctors and Medical Issues; Friends and Dating or Sexuality plus much more.

KP6194CI **$15.95**

BEHAVIOR

The Anti-Bullying Handbook
Keith Sullivan

Written for Parents, teachers, administrators, counselors, therapists this resource can help us to understand what bullying is and how to arrest it or to prevent it. Part I gives a clear overview of what we understand about bullying and Part II provides information on how to deal with with bullying.

OU3884BE **$19.95**

Raising Children Who Refuse to Be Raised
Dave Ziegler, Ph.D.

This book is for both parents and professionals who are involved with the care of children who have severe emotional or behavioral disturbances as the result of abuse or neglect. The three major sections cover: Emotional disturbances, Where it all Begins; Behavioral Disturbances. There is More than Meets the Eye; and lastly Advanced parenting Skills and Challenges. The 12 chapters contain detailed discussions of emotional or behavioral disorders, their causes and possibilities for treatment.

AC8777BH **$19.99**

ASPERGER SYNDROME

Blue Bottle Mystery
Kathy Hoopmann

A warm, funfilled fantasy story that enables children with Asperger syndrome to read about their disability in a non threatening way that promotes the best in them.

TT9785 **$11.95**

Asperger Syndrome, the Universe, and Everything
Kenneth Hall

The author was diagnosed with Asperger Syndrome at age eight, and now he describes some of the inner experiences and perceptions a child with autism has from a unique perspective that only one who has been through it can truly explain.

TT9300AS **$11.95**

Of Mice and Aliens
An Asperger Adventure
Kathy Hoopmann

Ben, recently diagnosed with Asperger Syndrome, and his friend Andy uncover an alien spaceship that crash landed in their backyard. With Ben trying to cope with his disorder, and the alien trying to cope with life on earth, adventure ensues.

TT0073AS **$11.95**

SPINA BIFIDA

An Introduction To Spina Bifida
David G. McLone, M.D., Ph.D. and Joy Ito, R.N.

The purpose of this book is to aid the parents, family and non-medical people who care for the child born with spina bifida. Revised 1998

SB0955B **$6.00**

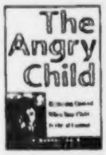
Answering Your Questions About Spina Bifida
A Guide from the Spina Bifida Program Department of General Pediatrics
Edited by C. Shaer

Available in Spanish

Contains information to help understand basic medical, educational, and social issues of children and adults with spina bifida.

CN1525B-ENGLISH **$6.95**
CN1535B-SPANISH **$6.95**

PARENTING



The Angry Child
Regaining Control When Your Child is Out of Control
Tim Murphy, Ph.D.

Anger can be a normal response to frustration or disappointment, but for some children it is an ingrained behavior that caused them and those around them needless misery. This book provides both the roots and the solutions for uncontrollable anger in children. Learn the 10 characteristics of the angry child, Four stages of anger and how to cope, the 5 C's of successful parenting and much more.

RH676XPA **$24.00**

Father Need
Why Father Care Is as Essential as Mother Care for Your Child
Kyle D. Pruett, M.D.

An easy to follow handbook which offers in depth advice for parenting children of all age groups from infancy through adolescence and adulthood. Learn not only why a father needs to take an active role in raising children, but also how to do so effectively.

RH737XPA **13.95**

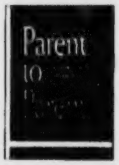
Sign up for E-mail notices of Internet specials! Call 800-535-1910 to subscribe.

EP LIBRARY • (800) 535-1910 • EPLIBRARY@AOL.COM

SPECIAL KIDS NEED SPECIAL PARENTS
A Resource for Parents of Children with Special Needs
JUDITH LOSEFF LAVIN

Parents of children with special needs face unique emotional and practical challenges every day. These issues are seldom fully addressed by the medical community—an parents' most compelling questions remain unanswered. The author draws upon interviews with health care professionals, nationally recognized authorities and families of special need children to give readers the advice, encouragement and comfort they crave.

GP6622PA **$13.95**

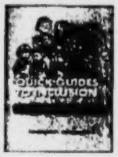


THE PARENT TO PARENT HANDBOOK
Connecting Families of Children with Special Needs
BETSY SANTELLI, FLORENE STEWARD POYADUE, JANE LEORA YOUNG

As a parent you have lots of questions, If you child has a disability you probably have even more. One of the best ways to find answers to your questions is through "Parent to Parent Programs". Written by two mothers that have been there this book will explain how these valuable programs work and how they can give you the help you need.

PB4979GN **$29.95**

INCLUSION



QUICK GUIDES TO INCLUSION
Ideas for Educating Students with Disabilities
MICHAEL F. GIANGRECO

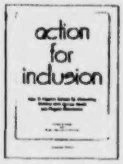
With brief factual summaries and to the point suggestions, the book is easy to use and focused on the topics most essential to successful inclusion. An entry level guidebook for new teachers and a concise summary of practices for seasoned professionals.

PB143ED **$22.95**

THE ILLUSION OF FULL INCLUSION
A Comprehensive Critique of a Current Special
JAMES M. KAUFFMAN AND DANIEL P. HALLAHAN

A collection of analyses by nationally recognized individuals who raise serious questions about the full inclusion of all students with disabilities into general education.

PE178IN **$31.00**



ACTION FOR INCLUSION
How to Improve Schools By Welcoming Children with Special Needs Into Regular Classrooms
O'BRIEN AND FOREST WITH SNOW, PEARPOINT, AND HASBURY

An extraordinary plain language guide to inclusion. Provides a clear presentation of the values behind full inclusion and outlines a sensible series of actions that can be followed to make full inclusion a reality.

IP700ED **$15.00**

AUTISM

THROUGH THE EYES OF ALIENS
A Book About Autistic People
JASMINE LEE O'NEIL

This is a rich and positive description of how it feels to be autistic and how friends, family and the professionals that work with autistic people can be more sensitive to their needs. Written with a creative spin by an author who is autistic herself.

TF009AT **$24.95**

EXITING NIRVANA
A Daughter's Life with Autism
CLARA CLAIBORNE PARK

The sequel to "The Siege", this book finds Jessy Park, now an adult, still struggling with language, with hypersensitivity's and obsessions, and with the social interactions that ordinary people take for granted but she cannot understand. With the help of family, teachers, and friends, Jessy has achieved more than her parents could have hoped for. This is a moving story about the making of a self and what it means to be human and a contributing active member of her family and community.

LB1178AT **$23.95**

REACHING OUT, JOINING IN
Teaching Social Skills to Young Children with Autism
MARY JANE WEISS, PH.D., BCBA & SANDRA L. HARRIS PH.D.

Designed to show parents and professionals how to help young children with Autism with one of their most challenging areas of development—Social behavior this book covers four broad topics. This book focuses on the following areas: play skills; the language of social skills; understanding another person's perspective; and using these skills in an inclusive classroom. This guide offers invaluable expertise and easy to understand activities parents and teachers can practice at home or at school to help kids with autism in preschool through elementary schools become more socially adept.

WB7240AT **$16.95**

SON RISE
The Miracle Continues
BARRY NEIL KAUFMAN

An inspiring journal of a family's successful effort to reach their autistic child. Includes stories of other families who have used the same approach to heal their special children.

OI085AM **$20.00**

AUTISM THROUGH THE LIFESPAN
The Eden Model
DAVID L. HOLMES, ED.D.

A unique and detailed look at a successful approach to treating and caring for children with autism. Parents, teachers, and treatment professionals will find this book to be informative and insightful reading.

WB176AT **$21.95**

ATTENTION DEFICIT

UNLOCKING POTENTIAL
College and Other Choices for People with LD and AD/HD
JULIANA M. TAYMANS, PHD, LYNDA L. WEST, PHD, AND MADELINE SULLIVAN, M.A.

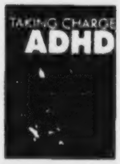
This book is an indispensible tool for high school students with learning disabilities who are preparing for life after graduation. Filled with the latest information, advice, as well as practical tips and resources, this book is designed to make the transition from high school a success.

WB9948AD **$18.95**

DISTANT DRUMS, DIFFERENT DRUMMERS
A guide for young people with ADHD
BARBARA D. INGERSOLL, PH. D.

A view that offers children and adolescents struggling with ADHD the opportunity to see themselves in a positive light due to their penchant for novelty and exploration and boundless energy.

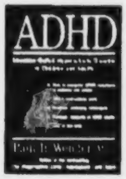
CP100AD **$15.95**



TAKING CHARGE OF ADHD
The Complete, Authoritative Guide for Parents
RUSSELL A. BARKLEY, PH.D.

This revised edition has been updated to incorporate the most current information on ADHD and its treatment. Includes a step by step plan for behavior management; New strategies that give children greater chances of success at school and in social situations; Practical advice for parents on managing stress and keeping peace in the family plus much more.

GL5606AD **$18.95**



ADHD
Attention Deficit Hyperactivity Disorder in Children, Adolescents, and Adults
PAUL H. WENDER, M.D.

This book is filled with extensive case histories of children and adolescents with ADHD. It contains valuable information on where to seek help, as well as on the kinds of diagnostic tests currently available. This is a must have for parents of children with ADHD.

OU3497AD **$10.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: EP, Dept. EP0402, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call 800•535•1910

QTY.	ITEM#	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item, 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

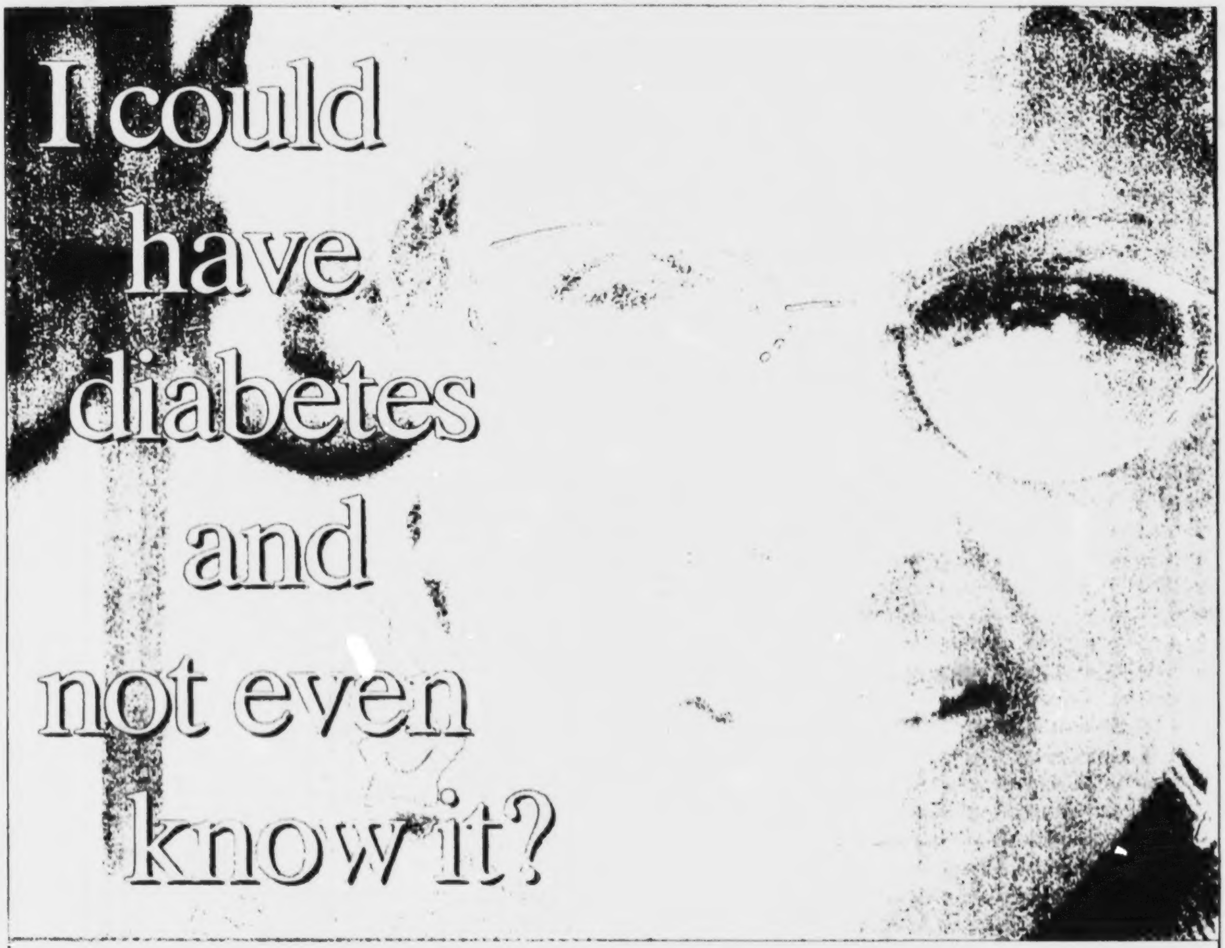
U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

These prices are subject to change without notice.

Name ____________________
Address ____________________
City ____________________ State __________ Zip __________
Telephone ____________________ E-Mail ____________________
I have enclosed my check payable to EXCEPTIONAL PARENT or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover
Account Number: ____-____-____-____ Exp. Date ____/____
Signature ____________________

Circle #200


I could have diabetes and not even know it?

Then why would I want to know?

Diabetes can lead to heart disease, stroke, kidney disease, amputations and blindness! What's scary is that there are often no symptoms.

If you're over forty-five, you don't exercise, and you're overweight, you're at risk!

What should you do? Get a simple blood test. Because with early detection and treatment, diabetes can be kept under control.

For more information, call
1-800-DIABETES
(1-800-342-2383)
or visit **www.diabetes.org**

American Diabetes Association®
Cure • Care • Commitment™

PART X

The Use of Sedation for the DENTAL PATIENT WITH SPECIAL NEEDS

by Nancy Dougherty, DMD, Maureen Romer, DDS, MPA and Steven P. Perlman, DDS, MScD

Before your child is scheduled for a sedative procedure in a dental office, make sure that the practitioner has the appropriate certification required by your state for the type of sedation to be administered.

There are various indications for the use of sedation in dental patients with disabilities. These can include: patients who are unable to cooperate because of extreme anxiety or phobia concerning dental treatment; individuals who exhibit involuntary movement caused by neuromuscular disorders; and patients who, due to mental retardation, are unable to understand the need for dental care and are unable to cooperate in a way that allows the dental professional to provide optimal care. Additionally, some patients capable of cooperating for brief, minor procedures may require sedation for more extensive treatment needs. The decision to utilize a sedative medication should be made only after a thorough evaluation of dental treatment needs has been completed, a level of patient cooperation has been attained and the patient's current health status assessed.

Dental professionals are trained in a number of sedative techniques that can alleviate patient anxiety and/or control disruptive behaviors in the course of dental treatment. Laws regulating sedative administration by dentists vary widely from state to state. Before your child is scheduled for a sedative procedure in a dental office, make sure that the practitioner has the appropriate certification required by your state for the type of sedation to be administered. It is very important that you completely familiarize the doctor with your child's medical history and provide information on any medications your child may be taking.

Sedative techniques run along a continuum from light, conscious sedation, through unconscious sedation, all the way to general anesthesia. The degree of sedation is dependent upon the drugs utilized as well as the dosage and route of drug administration.

Types of Sedation

Inhalation: The combination of nitrous oxide and oxygen (commonly known as "laughing gas") is the most commonly employed sedative agent in dentistry. As used in dental offices today, nitrous oxide is not a particularly potent sedative. It is, however, highly effective in inducing relaxation in patients with anxiety. One of the biggest advantages of nitrous oxide is its relative safety compared to most other sedative agents. Its rapid onset of action and short recovery time also contribute to nitrous oxide's value as a conscious sedative agent. In fact, complete recovery from

continued on page 114

continued from page 113

the effects of nitrous oxide usually occurs within three to five minutes of pure oxygen inhalation. A drawback to the administration of nitrous oxide is that the procedure requires a degree of patient cooperation. Since the patient must be willing to wear a nasal hood and understand the need to breathe through the nose in order for the drug to be effective, the procedure will probably be ineffective with individuals with extremely disruptive behavior or those with significant cognitive deficits. Nitrous oxide sedation can also induce nausea and vomiting in some patients. Because of this, it is advised that patients not eat prior to receiving nitrous oxide.

Oral: Most pediatric dentists are trained in the use of some oral sedative medications and many practitioners utilize them. The oral sedative most frequently used by pediatric dentists is midazolam. Other oral sedatives commonly encountered in dentistry are *chloral hydrate, hydroxyzine* and *diazepam*. All of these medications are considered conscious sedative agents and, in most cases, the patient will remain awake during the dental procedure.

Some practitioners may use combinations of oral medications to enhance the sedative effect. These oral medications may also be used in combination with nitrous oxide sedation and/or physical restraint. The major advantage of oral medication is the ease of administration. The only patient cooperation required is the willingness to swallow medication. Disadvantages include a fairly slow onset of action (at least 30 minutes) and variable levels of effectiveness from patient to patient. Patient anxiety level, metabolism and rate of absorption through the stomach can all have an impact on the duration of action and effectiveness of oral sedative medications; a dosage that provides adequate sedation for one individual may be ineffective in another person the same age and size. An additional disadvantage to oral sedatives is the inability to quickly reverse the action of the drug.

Intramuscular (IM): Intramuscular injection of sedative medication is another technique used in some dental offices. It involves the injection of medication into areas of high muscle mass, usually the upper arm, buttock or thigh. IM administration has several advantages over orally administered medication. It has a more rapid onset of action and more reliable absorption than the oral route. It can also be useful for a patient who is resistant to swallowing medications. However, the IM and oral routes of sedative administration share many disadvantages. As with oral administration, it is impossible to predict on a consistent basis the most effective dose of injected sedative for each patient. The inability to quickly reverse the action of a drug injected intramuscularly is another shortcoming. IM sedation can be useful for fairly brief procedures or as a premedication for disruptive patients to allow subsequent placement of an intravenous (IV) line. *Ketamine* is one of the medications frequently used for IM sedation.

Intravenous (IV): IV sedation is used primarily by oral surgeons and, to a lesser extent, by general and pediatric dentists trained in the technique. In some instances, a specialist in dental anesthesia will perform the sedation and monitor its performance. IV sedation has a rapid onset of action and, in most cases, is very effective. Because the patient has an IV in place throughout the procedure, additional medication can be administered as needed. The level of sedation can thus be better controlled than with the oral or IM techniques, and also permits the completion of lengthier procedures. Emergency drugs can also be administered through the IV if necessary.

The major disadvantage to IV sedation is that the patient must be cooperative during venipuncture (insertion of the needle into a vein). This may be difficult to accomplish with either young, fearful children or patients with resistant behavior. Several different medications are available for use as IV sedatives. The practitioner will determine which drug is the most appropriate for each patient based on factors such as the length of the anticipated procedure and the patient's medical status.

For many patients, in-office sedation may be more desirable than general anesthesia performed in the hospital because it is more cost-effective. However, it may be difficult to find dental practitioners who are trained and certified to perform sedation in their offices. Also, some individuals who have extensive treatment needs or medical compromises may be more appropriately treated in the very controlled environment of a hospital operating room.

Hospital Dentistry

General Anesthetia: If the child or adult patient cannot be treated safely and effectively in the office environment by utilizing the previously discussed techniques, the alternative would be treatment in the hospital operating room under general anesthesia. The criteria clinicians use in making the decision to treat a patient under these circumstances will vary greatly depending on their level of skill and treatment philosophy. The utilization of either physical or mechanical restraint, or premedication and sedation, should be satisfactory to treat the vast majority of patients with special needs. Only for a limited number of cases under specific circumstances should general anesthesia be considered as a preferred alternative in the delivery of care.

For general anesthesia to be considered, a thorough patient examination must be completed so that the clinician is completely prepared to face any situation that may arise in the operating room. No matter how much restraint is necessary or how difficult it is to obtain, a thorough examination must be completed with even the most resistant, non-compliant, uncooperative patient.

If the decision to utilize general anesthesia is made to improve behavior management, there must be attempts to accomplish the dentistry with or without restraint. The decision for hospitalization is usually based on the amount of required dentistry and the patient's level of cooperation and medical condition.

In hospitalizing an infant or a child needing dental care, age alone should not be the deciding factor. Most infants and children can be safely and effectively treated in the office by a variety of techniques. Medical conditions beyond a patient's disability that may contribute to the need for hospitalization include cardiac or respiratory issues or, perhaps, a severe neurological disorder.

In addition to these criteria for children, adolescents may present behavioral issues that the clinician may not be able to manage because of their patient's physical stature (i.e., height and weight). The amount of necessary dental care is not a factor if the patient can be safely treated with multiple visits.

The decision for hospitalization is usually based on the amount of required dentistry and the patient's level of cooperation and medical condition.

Adult patients may have the following dental needs: severe periodontal (gum) disease requiring surgery; problems with wisdom teeth, including impactions requiring complicated oral surgery; or the need for a significant amount of restorative dentistry (fillings).

Behavior management and the inability to perform these procedures under any other circumstances are indications for general anesthesia. The same criteria would hold true for the geriatric patient with special needs.

If the clinician decides that general anesthesia is the only viable alternative for care delivery, then the first step is for the dental staff to consult with the primary care physician. Two important questions must also be answered. The first question is whether or not the patient is medically competent to undergo the procedure. The second is whether hospitalization will permit medical personnel to perform additional tests that the patient's inability to cooperate would otherwise prevent.

Virtually any medical procedure can be accomplished in addition to the dental rehabilitation. Any type of blood test can be done and drug levels can be checked to determine if they are within normal limits. Any type of examination, including gynecological, gastroenterological, visual and auditory examinations, can be done. Radiographs can be obtained and ultrasound procedures can be performed. Minor surgical and/or plastic surgery also can be performed.

When the patient is under general anesthesia, a four-, five- or even six-hour procedure is not uncommon. The key is to utilize the opportunity to complete as many necessary medical and dental procedures as possible.

In addition to the medical personnel, dental specialists may be part of the operating team. This may include oral surgeons, endodontists (root canal specialists), periodontists (gum), prosthodontists (crown and bridge) or pediatric specialists. Pediatric dentists are often the primary health provider for adults with disabilities due to the nature of our health care delivery system.

Once the plan for the dental rehabilitation is established, the case can be scheduled and usually done in the hospital's surgical day care facility. Surgical day care centers are designed for patients to be discharged the same day following sufficient time in the recovery room and post-op areas. When patients are alert, have voided, are afebrile (do not have a fever) and tolerate clear fluids, they can then be discharged to their families or caregivers.

Another factor that must be considered in the overall treatment plan is cost. Hospital dentistry is very expensive and a case that lasts several hours can cost between $4,000 and $12,000, not counting any of the fees for medical or dental procedures. That figure only covers operating room time, anesthesia fees, recovery room and postoperative care. These cases all require preauthorization from either private insurance or Medicaid programs.

Another important issue is that legal consent must be obtained prior to hospitalization. If the patient is his or her own legal guardian, or if a family member or caregiver is guardian, this is not a problem. However, there may be a court-appointed legal guardian who is not readily accessible. In any event, proper legal consent must be obtained.

It must also be realized that before general anesthesia is administered, a proper blood work-up and a chest radiograph (X-ray) are necessary and customary. For patients with behavioral considerations, these important diagnostic pretests may be impossible to obtain, and so present a risk. Therefore, not every hospital or medical staff may be willing to accept these dental rehabilitation cases.

In summary, oral rehabilitation under general anesthesia is an important and, quite possibly, the only viable option to deliver safe, quality and comprehensive dental care for the exceptional patient with special needs. **EP**

Nancy Dougherty, DMD, is an Assistant Professor in Dentistry and Pediatrics, Albert Einstein College of Medicine and Director of the Special Care Dental Program, Children's Evaluation and Rehabilitation Center, the Rose F. Kennedy Center, Albert Einstein College of Medicine, Bronx, NY.

Maureen Romer, DDS, MPA, is an Assistant Professor in Dentistry and Pediatrics, Albert Einstein College of Medicine and Assistant Director of the Special Care Dental Program, Children's Evaluation and Rehabilitation Center, the Rose F. Kennedy Center, Albert Einstein College of Medicine, Bronx, NY.

Steven P. Perlman, DDS, MScD, is an Associate Clinical Professor in Pediatric Dentistry at The Boston University Goldman School of Dental Medicine and Global Clinical Director of Special Olympics Special Smiles, Boston, MA.

research reflections

SSI and Employment Opportunities for Young Adults with Retardation: Safety Net or Bungee Cord?

by Jan Blacher, PhD

April seems like an appropriate month to write about "income." My grandfather always used to exclaim, "Be happy you have to pay taxes! That means you're making money!" However, there aren't many individuals with disabilities who make enough to worry about paying income tax. In fact, the economic outlook for people with disabilities is not particularly promising, especially after they leave high school. Technological advances have provided tremendous employment opportunities for individuals with physical disabilities, but for those with cognitive disabilities, successful employment outcomes have been far fewer.

There is some good news here, though. "Disability Determination for Mental Retardation," a report released recently from the National Research Council, focuses on the scientific base and current clinical practices in diagnosing mental retardation for the purpose of awarding disability benefits. Individuals with mental retardation comprise the largest diagnostic category of children receiving supplemental security income (SSI), 26.4 percent of the total, and thus are the focus of this report. Many parents and service providers don't realize that receipt of benefits from the Social Security Administration (SSA) programs can provide a "critical gateway" to other federal and state benefits.

While the report from the National Research Council has most relevance for individuals who have IQ scores at or around 60 to 70 (known as having "mild mental retardation"), it has implications for other disability recipients, their parents or careproviders, and professionals who provide services to this population. The report is based on state-of-the-art research in disability and mental retardation, and thus is oriented toward a scientific as well as a policy perspective.

What's new about this report?

The French have a saying, *plus ça change, plus c'est la même chose*. So, too, with definitions of retardation, "the more things change, the more things stay the same." It is important to know that the definition of mental retardation (MR) used by the SSA differs somewhat from that of many major professional and healthcare organizations. Indeed, as you read this, the American Association on Mental Retardation (AAMR) is considering, again, both a name and a definition change. Here are the aspects of SSA's definition that are relevant for eligibility purposes.

The current practice of considering both intelligence (as measured by traditional IQ tests) and adaptive behavior as critical components of MR will continue. The new recommendations pertain to the specific types of instruments to be used in determining eligibility. For example, for testing IQ, the committee recommends using only comprehensive, multi-factored (statistically defensible) intelligence tests that have recent and valid norms. The child, youth or adult tested must have a total IQ score (sometimes called a "full" or "composite" score) at or below 70, or a part score (i.e., score on a subsection of the IQ measure) at or below 70. Still under debate by the SSA is whether a composite score out of the mental retardation range will be accepted in the presence of a low part score. The report lists acceptable instruments for infants, children and adults, and many of the names are recognizable: Bayley Scales of Infant Development-II; Kaufman Assessment Battery for Children; Stanford-Binet Intelligence Scale, Fourth Edition; Wechsler Intelligence Scales (for preschool, children, adults).

Adaptive behavior is still a key dimension of mental retardation, and again, standardized instruments are recommended. Recommendations for adaptive behavior, as for IQ, are further divided by age and associated developmental expectations (infancy/early childhood, birth-4; childhood, 5-17; adolescence/adulthood, 18 and older). Actual domains of adaptive behavior vary more obviously by developmental level. For example, academic skills don't become critical adaptive components until the school-age years, and work-related skills don't enter into the picture until adolescence or adulthood.

In addition to recommending more reliable and scientifically valid instruments for determining MR, the report offers a number of recommendations about carrying out the determination process itself. As always, when an evaluation of their child is concerned, parents may wish to seek information about their examiner's credentials and the instruments selected for use in assessment, especially when seeking determination of MR for SSI eligibility purposes. Still, IQ and adaptive behavior assess-

Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, and had been a researcher for over 25 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of retardation, dual diagnosis,and the transition to adulthood. Dr. Blacher has developed **Research Reflections** as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to **Research Reflections** and any suggestions you might have. Send e-mail to: jan.blacher@ucr.edu.

ment remain the key components in determining eligibility.

Your children will also be eligible for benefits if they have a total IQ score of 59 or less, or if they have any other condition so disabling it interferes with a determination of true intelligence; such conditions could include blindness, deafness, uncontrolled seizures, or cerebral palsy.

Does SSI have anything to do with my child's schooling?

IDEALLY, it should! The future employability of children with mental retardation is clearly influenced by the preparation they receive during their formal, usually public, schooling. Since the passage of the Individuals with Disabilities Education Act Amendments of 1997 (IDEA '97), schools have been mandated to develop Individualized Transition Plans, or ITPs, for all adolescents with disabilities. This process should begin at age 14, or younger, if so determined by the child's IEP team. At least 200,000 young people with disabilities are exiting the school system each year and entering the adult world. The cornerstone of most ITPs is the generation of a plan to prepare the young adult for employment. The development of these plans should involve input from, and an interview with, the adolescent whenever possible, to determine preferences and skills. Parents, too, should be substantively involved in the development of this vocational plan.

The National Research Council report notes that, regardless of an adolescent's specific disability, discussion of work-related issues in the ITP should include information about SSI. Ironically, individuals with milder disabilities, specifically mild mental retardation, are at high risk of dropping out of high school, thus losing the support of the special education system. Once they are away from any formal service system such as school, these young people may not even have a chance to find out about SSI, much less know how to apply. SSI does indeed constitute a critical safety net for this vulnerable group, and we need to make sure that all eligible people can access this crucial system of support.

Do I need to think NOW about my child's employment after high school?

It's never too early to think about our children's future. However, many parents of children with mental retardation or other cognitive disabilities put off thinking about their children's future employability. The core concepts of this transition from school to work, as identified by most researchers, include: (1) involvement in meaningful and worthwhile activities in

continued on page 118

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

Early hyperbaric oxygenation therapy (HBOT) is a promising treatment for cerebral palsy and the brain-injured child. A recent symposium presented documentation from 17 countries substantiating the positive effects, which may even benefit the fetus in utero by having the mother undergo HBOT.

While hyperbaric oxygen treatment proved effective in older cerebral palsy patients (the oldest CP patient was treated successfully in the UK at the age of 59), substantial evidence from around the world strongly suggests that early intervention brings about superior results. An Italian study revealed that problems detected in a fetus may be treated in utero by placing the mother in a chamber. In Mexico and other areas, newborns with problems associated with a lack of oxygen are taken from the delivery room to a chamber. Frequently, in as little as one hour, HBOT may alter a child's entire life.

At the **Ocean Hyperbaric Neurologic Center**, we have treated patients as young as six weeks of age. With proper chamber pressure and treatment techniques, there are very few side effects. This early intervention does not preclude the treatment of older children. However, the earlier the treatment, the faster the improvement.

Coming Soon!

Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child

by R. A. Neubauer, M.D.

Dr. Neubauer's new book is a complete guide written for the professional as well as the caregiver of exceptional children. The book describes the latest information on hyperbaric oxygenation therapy including improved brain function as visualized through functional imaging. Clinical and scientific data along with references are included.

Call 1-800-552-0255 to order.

(800) 552-0255
• Call for free video & information

For more information, visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

Circle #63 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of hyperbaric oxygen therapy. For Editor-in-Chief statement see our Contents page.

research reflections

continued from page 117

the broader community; (2) some form of independent living (outside of the family home); and (3) economic self-efficiency.

While employment receives nearly all the attention in the literature on research and practice, practical applications of the transition concept developed in IDEA '97 do exist. Carolyn Hughes at Vanderbilt University and her colleagues have developed a Transition Support Model that makes 600 or so transition strategies available to practitioners and parents in *The Transition Handbook* (Paul H. Brookes, 2000). This book promotes the philosophy that people cannot be expected to function at their best in all post-secondary-school environments, and therefore careful choices need to be made. Furthermore, some adolescents and young adults will need more—or less—support in areas of work and adaptation to community living.

With such supports, Hughes and her team might argue that anyone can be successfully employed. However, the SSA makes supplemental security income (SSI) available for those who cannot obtain or maintain such employment because, for whatever reasons, local employers are ill equipped to provide necessary supports or because, even where these supports are in place, their existence cannot always be guaranteed. Thus, only by allowing young adults to become immediately re-eligible for SSI at the point of employment loss will this program truly be a safety net; otherwise, it might as well be a very large bungee cord.

To sum up

The old adage that "the only thing you can count on in life is death and taxes" may not hold true here. You can also count on the fact that Social Security has established a nationwide network of community-based organizations to provide benefit planning, assistance and outreach to individuals with disabilities who want to work. (Web site, http://www.ssa.gov/work/). Moreover, support models that involve collaboration among researchers, teachers and parents will continue to smooth the transition from high school to employment. Of course, fluctuations in the overall national economy will always have a substantial influence on government benefits and entitlements, but current trends indicate that SSI can provide the needed safety net for all persons with mental retardation in financial need. **EP**

This article was based on the following report: National Research Council (2002). Disability determination for mental retardation. Committee on Disability Determination for mental retardation. Daniel J. Reschly, Tracy G. Myers, & Christine R. Hartel, editors. Division of Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press.

Never in my Wildest dreams...

"WHEN I FIRST CAME TO CROTCHED MOUNTAIN OVER 10 YEARS AGO, activities that were second nature prior to the automobile accident were challenging tasks. Today I am a college graduate and also have my drivers license.

Never in my wildest dreams would I have been able to do half of what I've achieved without the encouragement and help that I received at Crotched Mountain! I want to thank everyone at Crotched Mountain for helping me get my life back!"

—*Brent Reagan '93*
Crotched Mountain School

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield NH 03047
www.crotchedmountain.org
email: admissions@cmf.org

OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES
CROTCHED MOUNTAIN

Circle #29 or visit www.eparent.com/adinfo

Information and support for the special needs community

PARENTS ○ FAMILIES ○ PHYSICIANS ○ PROFESSIONALS

Exceptional Parent Magazine

Welcome Resources Technology **Edu/Toys** **Healthcare** Subscribe

eparent.com

New! Visit the EP Web site, EParent.com, and discover...

TOYS—The new eToys Web site (www.etoys.com) teams with EP's Web site, EParent.com (www.eparent.com) to offer ideas, information and imaginative toys for families with kids who have special needs. When parents, teachers or caregivers shop at eToys and visit the co-branded EParent.com site, they'll find hand picked toys and games, plus featured articles from EP Magazine. The site also features direct links to the EParent.com shop at eToys, and eToys products recommended by experts or reviewed by organizations chosen by EP Magazine.

EDUCATION—EParent.com's newly-constructed Education channel (EDU/TOYS tab) yields a wealth of current articles on topics such as IDEA, IEPs, assistive technology, transitioning and inclusion. These are supplemented by a growing directory of schools, camps & residences, which can be found in the "Directories" link of the "Resources" channel.

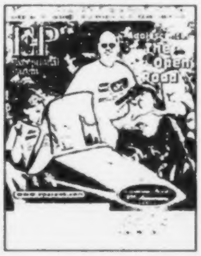
ON-LINE ARCHIVES—Now, EParent.com users can preform keyword searches through our on-line archives and purchase articles which have appeared, as far back as in the eighties, in EP Magazine (recipient of awards from Folio:The Magazine for Magazine Management, Easter Seals, Consumer Healthcare Group). These include classic pieces on such subjects as early childhood, rare disorders, technology, education, medical research update, transitioning, travel, all of which have distinguished EP Magazine through the years.

MORE TO COME IN 2002—You can also click through our EP Library (www.eplibrary.com) which contains books, videos and software encompassing almost 50 specific and general categories, with more than 650 titles. Of course, we will continue to refresh and improve EParent.com in 2002, and look forward to receiving your comments and suggestions. Log on and find out what we are all about!

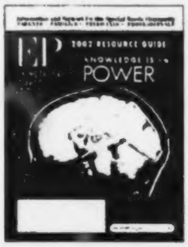
www.eparent.com

EP
Exceptional Parent

BOBBY
Click here for our Text only site.



NOW SUBSCRIBE ON-LINE



National Resource Directory

WWW.EPLIBRARY.COM
EP LIBRARY
THE SPECIAL NEEDS BOOKSTORE

TIGER PUSHCHAIR

The Tiger Pushchair is an adjustable seating system with an alternating wheelbase that can change from a stroller base to a Hi/Low indoor base. This unit features a reversible seat that can recline and tilt. It includes front locking swivel casters, adjustable seat angle and depth, and variable back width. The Tiger Pushchair folds easily for storage and transport. The Hi/Low Indoor base is sold separately.

Flaghouse, 601 Flaghouse Drive, Hasbrouck Heights, NJ 07604-3116;
Phone : (800) 793-7900; Fax: (800) 793-7922; Voice: (201) 288-7600: Fax: (201) 288-7887;
Web Site: http://www.flaghouse.com; e-mail:
sales@flaghouse.com

"B! buh bird tweet, tweet"

LEARNING SENSATIONS™ PLAY WITH LETTERS DESK

Learning Sensations Play with Letters Desk is an electronic toy with 26 textured and Braille letter tiles that provide three fun and stimulating ways to learn the alphabet. To activate the letter tile simply roll it across any hard surface up to three feet away from the desk. When activated, the tiles teach the alphabet by using corresponding phonics, words, music and colors. It offers tests on letter identification, color recognition and simple spelling. The desk features a writing surface, letter display area, volume control and automatic shut off. It also has a storage area and carrying handle for transport.

Fisher-Price Inc., 675 Avenue of the Americas, 2nd Floor, New York, NY 10010; Phone: (212) 620-8200: Fax: (212) 620-8380; Web site: http://www.fisher-price.com

FUN GRIPPER GOLF™

Fun Gripper Golf is a great indoor and outdoor game for children ages 2 to 6. It can be used as an aid in developing coordination and perceptual skills. The golf set includes three easy-to-grip clubs, two soft oversized balls and a nylon bag for transport. The Fun Gripper Golf Set comes in vibrant neon colors.

Fun-Attic, 3719 Jasmine NE, Grand Rapids, MI 49525;
Phone: (877) 293-5315, (616) 559-3642; Web site:
http://www.funattic.com; e-mail: sales@funattic.com

SULLEY

Sulley, a character from the movie "Monsters Inc.," is a switch-adapted plush toy. This blue and purple fuzzy monster speaks when a connected external capability switch is activated. Sulley says various phrases like, "Don't worry, I'll protect you!" and "You! Go to sleep now!" He even snores. When Sulley talks his scream canister lights up. Switch sold separately.

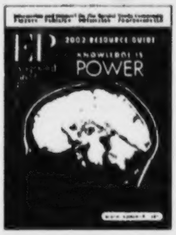
Enabling Devices/Toys for Special Children, 385 Warburton Ave., Hastings-on-Hudson, NY 10706; Phone: (800) 832-8697, (914) 478-0960; Web site: http://www.enablingdevices.com

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

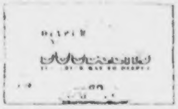


**EXCEPTIONAL PARENT
2002 RESOURCE GUIDE**

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/handling). To order, call 1-800-535-1910.

Circle #1

Diaper Doublers™



Diaper Doublers inserts that make cloth or disposable diapers more efficient, pulling moisture away from a child's tender skin

- Trim & Comfortable
- Overnight Protection
- Absorbency without Bulk
- Latex-Free for Sensitive Skin

www.DiaperDoubler.com

1-800-335-4434

Toll-Free Phone Orders

"The Drier Way to Diaper"™

Circle #2

freedom

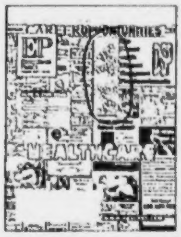
what is **your** definition?

call us today!

1.800.661.9915

www.freedomconcepts.com

Circle #3



EXCEPTIONAL PARENT

Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores All Across America. Every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books. $4.95 Cover Price.

Circle #4

INTRODUCING

the Invacare' Top End' Terminator' Jr. for kids who are going places!

[illegible]

©2001 Invacare Corporation. Invacare, Terminator, Top End and Yes, you can are trademarks of Invacare Corporation.

Circle #5

Natural Access™

Expand your horizons with the Landeez All-Terrain Wheelchair!

Rolls easily over sand, snow, gravel, and uneven terrain, so you can enjoy the outdoors

For more info 800-411-7789 or visit www.landeez.com

Circle #6

MARKETPLACE

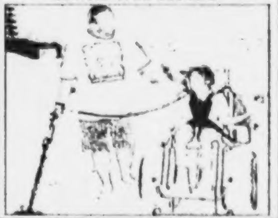
ATTORNEY

Attorney Richard Gottesman
(800)295-1107
gottesman@law.com
Cerebral Palsy, Brachial Plexus/Erb's Palsy and Childbirth Injuries

BEACH WHEELCHAIR

The Features Make All the Difference!

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure



FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg,
PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

Special-Needs Collection

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider. Resource information:
www.medmarket.com
e-mail: info@archhp

Ask about our Youth Brief sample pack. Only $5.99!

HDIS

FREE CATALOG

Call Today!
1-800-2MY-HOME™
(1-800-269-4663)

PARENT ADVOCATE

Visiting Nurse Service of New York has an excellent opportunity for an individual with experience rearing a child with a serious emotional or mental condition. Our mission is to empower families and maximize their strengths so that they may provide nurturing environments that support their children's development, advocate for needed changes in their children's service delivery systems, and become independent from the welfare system.

PARENT ADVOCATE

Family Connection Program
Brooklyn/Manhattan

Serve as an advocate for each family; assist Program staff and families in their efforts to find and obtain services from community agencies; and act as a liaison between the client and appropriate supplemental support services. Accompany clients to health, entitlement, educational, and other appointments. Requires a HS diploma or equivalent. Bilingual English/Spanish preferred.

We offer competitive compensation and a comprehensive benefits package. For immediate consideration, please submit your scannable resume (in Courier or Times Roman font, no bold, italics, underscoring or handwritten notations), with Ad Code EPM-040102-A, to Attn G. Gangadeen, via: Online: www.vnsny.org (preferred), E-mail: careers@vnsny.org, Fax: 212-504-7938, or Call: 1-866-VNS-TODAY. EOE M/F/D/V.

Visiting Nurse Service Of New York
We Bring The Caring Home

EXCEPTIONAL PARENT

Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores All Across America. Every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books. $4.95 Cover Price.

RESOURCES

JACKIE--
The HeartWarming, Inspirational, True Story of a Remarkable Down Syndrome Girl ...Plus... Parables for Parents of Down Syndrome Children

As told by Jackie's Father,
A Licensed
Mental Health Professional
DAN JUNOT, LPC, CCHT

A must read for all family members, friends, clergy, family doctors, pediatricians, caseworkers, special education teachers, and other professionals associated with newborn and young mentally retarded children!

You'll love reading *JACKIE!* 110 entertaining pages of laugh-out-loud, cry-out-loud stories...with a point: practical, experience-based advice for nurturing the full potential of special children. You'll revisit *JACKIE* again and again as your child grows. Includes 4 pages of color photographs, that depict and accompany her real life adventures.

Order by Internet, Phone or Mail:
www.centerforspecialservices.com
1-800-510-5235 (24 Hours)
CSS, INC • PO BOX 804
THIBODAUX, LA 70301

$23.00
+$4.00
S&H

ASK FOR ITEM# 715EP

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/ handling). To order, call 1-800-535-1910.

To Advertise in Marketplace Contact: **Barbara Nastro**

Tel: (908) 534-6366 • Fax: (908) 534-6941

MARKETPLACE

SEATING & POSITIONING

DESIGNED WITH CHILDREN IN MIND
Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Leckey products feature lighter mobile bases, more adjustable components, peer level positioning, child friendly positioning straps and playful colors.

- Freestander
- Totstander
- Easy Seat
- Advance Bath Chair
- Toilet/Shower Chair
- Basic Bath Support
- Pronestander

Call Sammons Preston today at 1-800-323-5547 for a complete Leckey® brochure.

EQUIPMENT DEALERS

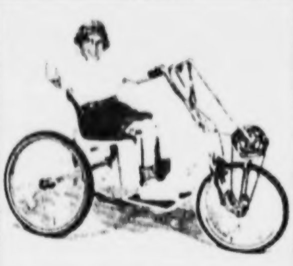
American
Discount Medical
Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

CYCLES



Cycles for Virtually Every Special Need & Age

Amputations, Cerebral Palsy, Spina Bifida, Visual Impairments/ Blindness, and many others

You Can Even Earn Your Own Cycle!
806-894-5700 FAX: 806-894-1238

Check us out on the Web...
http://www.rocknrollcycles.com

MONITORING SYSTEM

CARE ELECTRONICS INC.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price.
Call for FREE CATALOG

VAN CONVERSION DEALERS

MASSACHUSETTS

MOTION AUTOMOTIVE SPECIALTY
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—
Day, Week or Month.

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

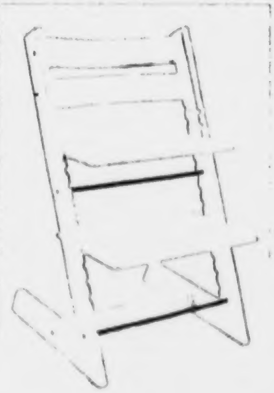
A SPECIAL SUMMER
for Children With Hidden Abilities

- Co-ed, residential, 7, 4, 3 week sessions
- Traditional, Adaptive/Therapeutic Recreational Programs for LD, ADD, ADHD, DD, PDD
- Located in beautiful High Falls, New York

Contact: Bruria K. Falik Ph.D.
Camp Huntington
P.O. Box 368
Woodstock, New York 12498
(845) 679-4903
Email: **camphtgtn@aol.com**
www.camphuntington.com

Camp Huntington

Circle #25 or visit www.eparent.com/adinfo



We Like Making Kids Happy ...

Send For Free Catalog

equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094
E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #35 or visit www.eparent.com/adinfo

"Train of Thoughts"

by Carlie Grippi

I ride on a train of thoughts,
I made a nick in time.
What does it mean to have bare feet?
And can you drink a whine?
Can you ever eat a date?
Or send a deck of cards?
And if I put three feet together,
would they fill the yard?
Does a finished book become bright red?
Can water really see?
Is a riverbank filled with money?
I've climbed my family tree.
Where is the head of the class?
I've given a dozen stares,
I wonder what the number ate?
I've seen those Easter hairs!
I've eaten the color orange,
and eaten little peas,
and I've stepped in a cherry pit,
and drunk a cup of tea.
I write my letters with a pigpen,
and swim in a game of pool.
Juries sit in tennis courts,
and all fish go to school.
Does blowing turning a whistle blue?
Do window shades go blind?
I take nice walks with candy canes,
and the ones who are smart will mind.
All of these words put together
mean different things as we see.
And I must say in my own words,
OUR LANGUAGE CONFUSES ME!

Carlie is 17 and attends the Ohio State School for the Blind. She plans to attend college after graduation and is considering Bowling Green State University or Gallaudet University. She would like to be a writer, perhaps even a songwriter. She enjoys all types of music, especially country music. Her favorite hobbies include running, swimming, writing, and hanging out alone or with friends. Carlie has CHARGE syndrome and uses a "Link" to communicate. The link is a voice output communication device much like a combination TTY/laptop computer. It has a visual display that reads what is typed. She is learning Braille and ASL. She has attended many summer camps and volunteers at her local MR/DD. EP

Thanks to the Great Lakes ARea Regional Center for DeafBlind Education for submitting Carlie's poem.

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number, and e-mail address! ***Now on the Web!*** We will now be including **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

A World Without Limits For Hearts That Know No Bounds

Life's A Trip – Travel In Style

Financial Assistance Comprehensive Adaptive Equipment Information

- $1,000 for the installation of adaptive equipment.[1]
- $200 for alerting devices, lumbar seats and running boards.[2]
- Solid information about selecting and installing adaptive equipment.

Ford Motor Company Products
Ford, Lincoln and Mercury cars, vans and light trucks of proven quality, durability, performance and value.

Ford Credit Mobility Financing
Flexible finance terms on both the vehicle and the adaptive equipment for qualified customers enrolled in the Ford Mobility Motoring Program.

Ford Motor Company
MOBILITY MOTORING
LINCOLN Ford Mercury

Order Your Ford Mobility Motoring Information Kit Today!

BEST COPY AVAILABLE

From Our Web Site:
www.ford.com/mobilitymotoring

From Our Telephone Response Center:
1-800-952-2248 or TTY 1-800-833-0312

[1] The Ford Mobility Motoring Program will reimburse for the exact amount of the adaptation up to a maximum of $1,000 on adaptive equipment and up to a maximum of $200 on alerting devices, lumbar support and running boards when you take new retail delivery of a 2001, 2002 or 2003 Ford, Lincoln or Mercury vehicle by August 31, 2002. Total reimbursement not to exceed $1,000.

[2] Factory installed air conditioning, lumbar seats, running boards and power windows options are not eligible for Ford Mobility Motoring Program assistance.

Circle #37 or visit www.eparent.com/adinfo

A Better Bedtime Story

The Vail Enclosed Bed

Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for your child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt. Plus, we provide assistance in obtaining insurance approval.

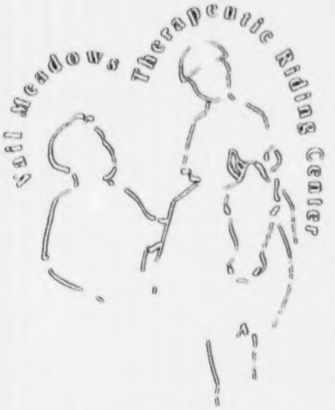
Available from home health-care products dealers, or direct from the manufacturer.

For a FREE catalog, call:
1-800-235-VAIL

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard


Vail Meadows Therapeutic Riding Center

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for challenged riders.

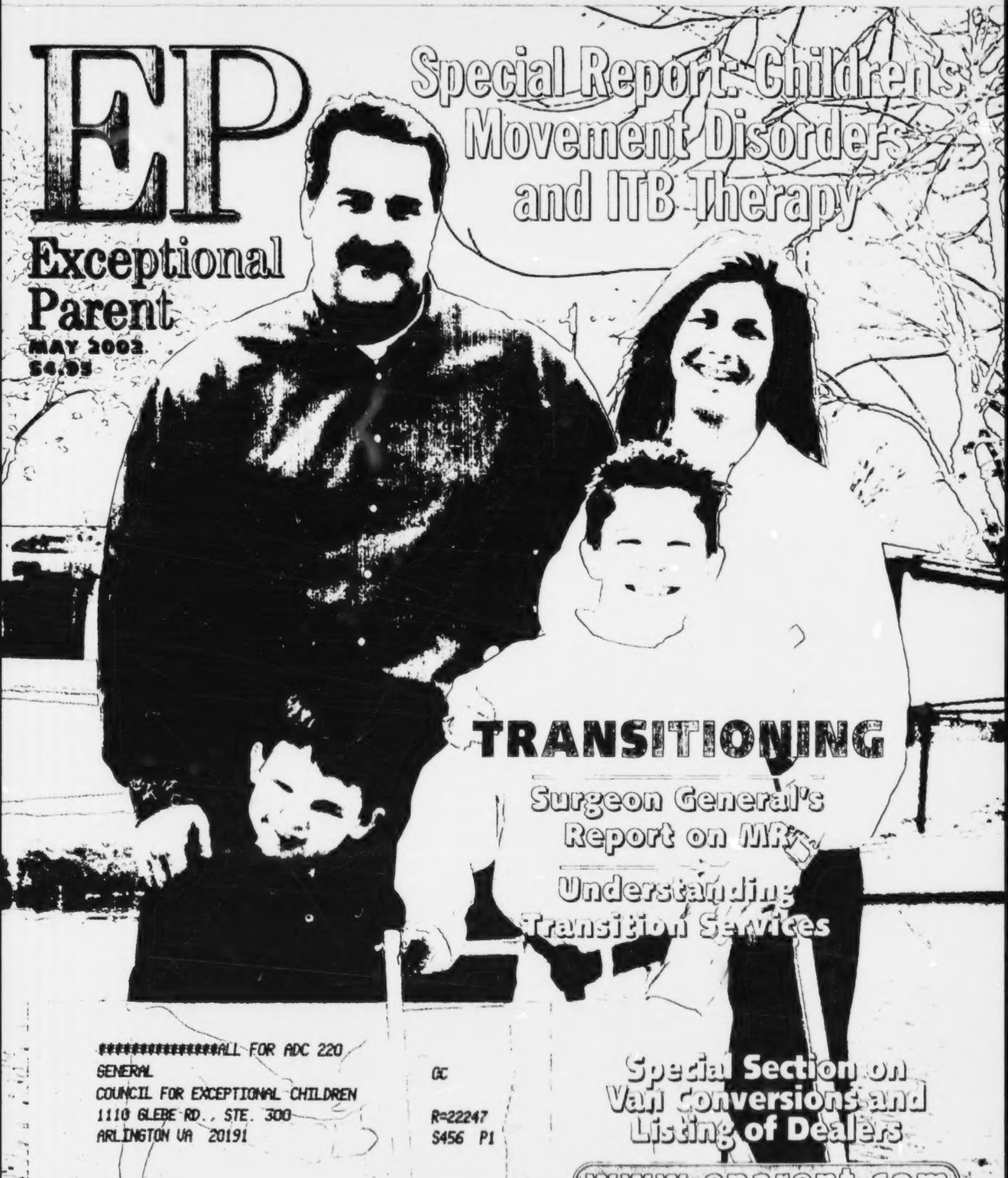
Ask about Our Decorator Accessories.

“Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep.”

Sheri Wittmer
Sandusky, Ohio

Circle #80 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS



EP
Exceptional Parent

MAY 2002
$4.95

Special Report: Children's Movement Disorders and ITB Therapy

TRANSITIONING

Surgeon General's Report on MR

Understanding Transition Services

Special Section on Van Conversions and Listing of Dealers

****************ALL FOR ADC 220
GENERAL GC
COUNCIL FOR EXCEPTIONAL CHILDREN
1110 GLEBE RD., STE. 300 R=22247
ARLINGTON VA 20191 S456 P1

www.eparent.com

BEST COPY AVAILABLE

For people with severe spasticity due to cerebral palsy, brain injury, or spinal cord injury

There is something you can do about severe spasticity. Oral medications may help some people with severe spasticity, but for many, it may not be effective or may cause intolerable side effects. When spasticity continues to interfere with the way you live, there is something you can do about it.

ITB™ Therapy (Intrathecal Baclofen Therapy) is an effective way to control severe spasticity. A medication called Lioresal® Intrathecal (baclofen injection) is delivered directly to where it's needed most — in the fluid that surrounds the spinal cord. In clinical studies, ITB Therapy reduced spasticity during the screening test in 97%[1] of people with severe spasticity due to multiple sclerosis or spinal cord injury, and in 86%[1] of people with severe spasticity due to cerebral palsy or brain injury.

Take the first step. Find out how the therapy can work for you. Talk to your doctor about the screening test, which uses a small amount of medication to test if it will work for you. For more information call us today at 800-664-5111 Ext. 220. Or, you can log on to www.spasticity.com.

ITB Therapy drug side effects are usually temporary and manageable by adjusting the dose. The most common side effects include loose muscles, drowsiness, nausea/vomiting, headache, and dizziness. Close attention to your doctor's instructions is required since abrupt discontinuation of intrathecal baclofen can result in high fever, altered mental status, returned spasticity, and muscle rigidity, and in rare cases has been fatal. (For more information, please read the attached Lioresal Intrathecal Patient Information on the back.)

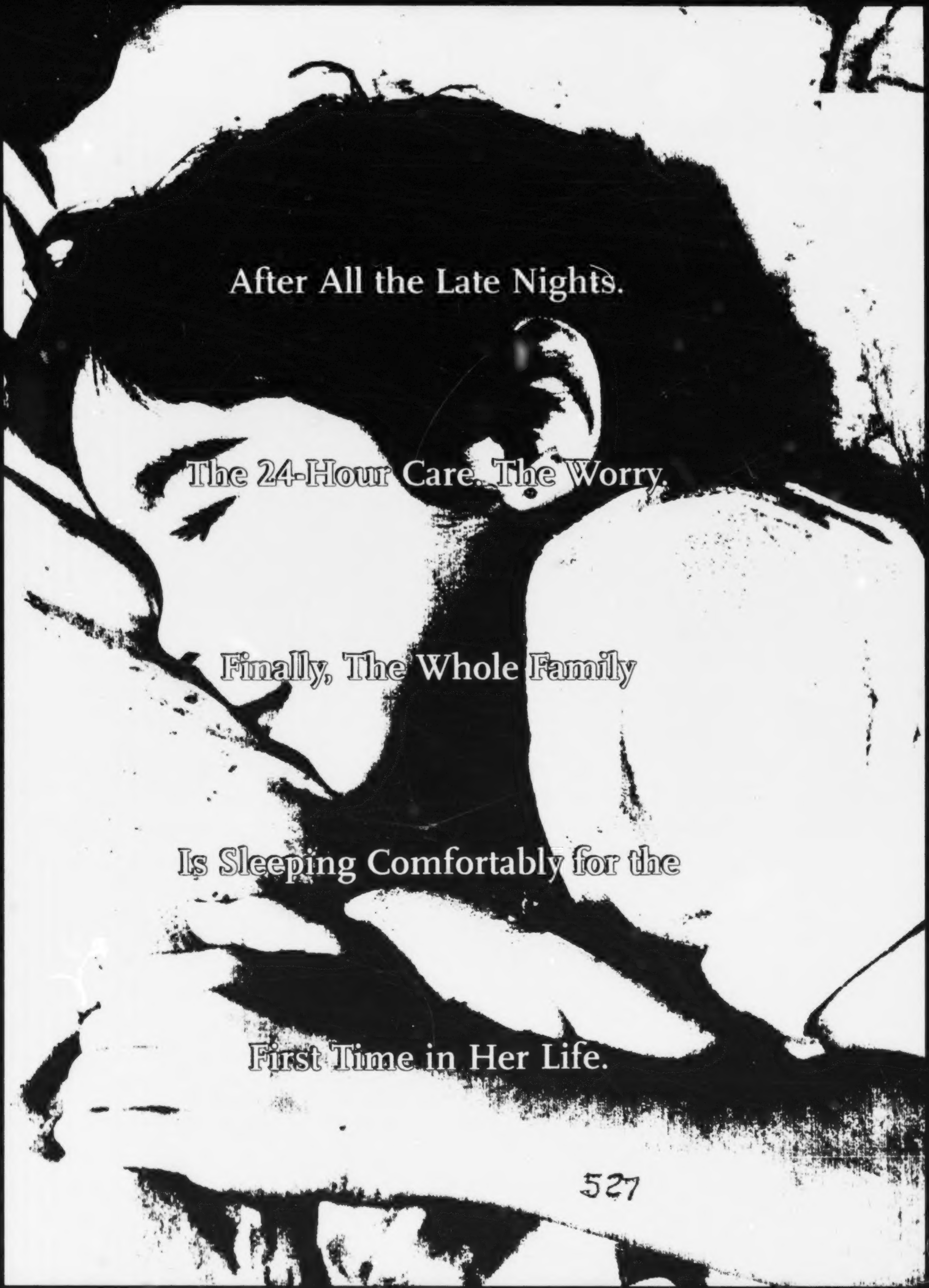
---

[1] Controlled clinical studies on file, Medtronic, Inc.

©2002 Medtronic, Inc.

Medtronic

When Life Depends on Medical Technology


After All the Late Nights.
The 24-Hour Care. The Worry.
Finally, The Whole Family
Is Sleeping Comfortably for the
First Time in Her Life.

Patient Information

LIORESAL® INTRATHECAL
(baclofen injection 10 mg/5 mL, 10 mg/20 mL, 0.05 mg/1 mL)

Completely read this information before you start using Medtronic ITB™ Therapy (Intrathecal Baclofen Therapy). This information does not take the place of thorough discussions with your doctor. You and your doctor should discuss ITB Therapy before you begin receiving the therapy and at regular refill appointments.

Q: What is Lioresal® Intrathecal (baclofen injection)?

A: Lioresal Intrathecal is a liquid form of baclofen, and is commonly used to treat severe spasticity. Liquid baclofen is used for injections and infusion into the intrathecal space (the fluid-filled area surrounding the spinal cord), using an implantable drug delivery system.

Q: What is severe spasticity?

A: Severe spasticity is tight, stiff muscles that make movements – especially of the arms and legs – difficult or uncontrollable. Severe spasticity can interfere with an individual's function and/or comfort.

Q Who is a candidate for Lioresal Intrathecal?

A: People who suffer from severe spasticity resulting from cerebral palsy, multiple sclerosis, stroke, traumatic brain injury, or spinal cord injury, and who suffer intolerable side effects from oral baclofen (pills), may be a candidate for Lioresal Intrathecal. A screening test will help determine if you will respond to the intrathecal medication. Talk with your doctor about whether Lioresal Intrathecal may be an option for you.

Q: Who is *not* a candidate for Lioresal Intrathecal?

A: People who are hypersensitive (extremely sensitive) to oral baclofen should not take Lioresal Intrathecal.

Q: What are the most common side effects of Lioresal Intrathecal?

A: The side effects of intrathecal baclofen include loose muscles, sleepiness, upset stomach, vomiting, headaches, and dizziness. As with most medications, overdose (drug dose is too high) or under dose (drug dose is too low) can occur. Talk with your doctor about the side effects you may experience from your treatment.

Q: What do I need to know if I am using Lioresal Intrathecal?

A: Abruptly stopping intrathecal baclofen can result in serious medical problems and in rare cases has been fatal.

Q: What are the signs of rapid or abrupt withdrawal from intrathecal baclofen?

A: Increase or return in spasticity, itching, low blood pressure, lightheadedness, and tingling sensation are often early indications of baclofen withdrawal. It is very important that your doctor be called right away if you experience any of the above symptoms.

In rare cases, severe symptoms may occur. These symptoms include high fever, altered mental status, spasticity worse than before you started ITB Therapy, and muscle rigidity. It is very important that your doctor be called right away if you experience any of the above symptoms.

Q: What can I do to prevent baclofen underdose or abrupt discontinuation of intrathecal baclofen?

A: It is very important that you keep all of your refill appointments. This may require some planning prior to traveling. Maintaining a regular refill schedule will ensure the pump does not run out of medication and that any potential problems with the infusion system are diagnosed and corrected. Additionally, you should be aware of what your pump alarms sound like. If you hear the alarm, contact your doctor immediately.

Furthermore, it is very important that you know and understand the signs of baclofen underdose. Also be sure to tell your doctor right away if you experience any unusual symptoms, side effects, or changes in your condition.

Q: What are the symptoms of baclofen overdose?

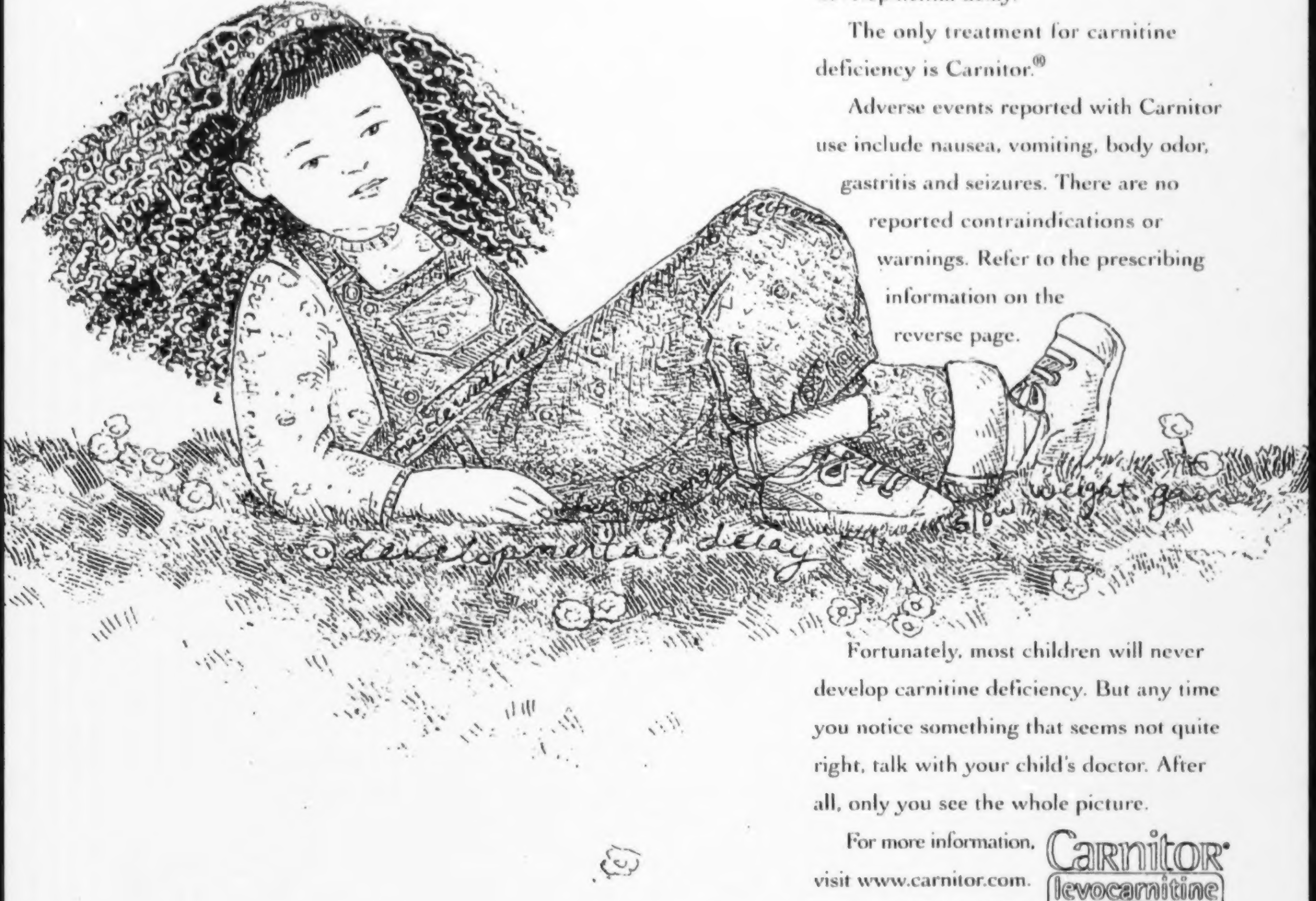
A: Although rare, it is possible for you to receive too much medication (overdose). A baclofen overdose may cause drowsiness, lightheadedness, respiratory depression (difficulty breathing), seizures, loss of consciousness and coma. If you experience any of the above symptoms, it is very important that you or your caregiver contact your doctor right away.

Rx only.

Lioresal® is a registered trademark of Novartis Pharmaceuticals Corporation.

This provides a summary of the most important information about Lioresal Intrathecal. If you would like more information, talk with your doctor. You can ask for information about Lioresal Intrathecal that is written for healthcare professionals. You also can get more information by visiting www.spasticity.com.

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?



No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.

Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

EP

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA 10

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

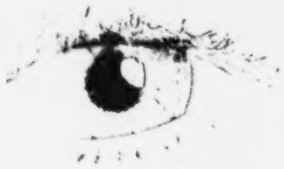
The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #77 or visit www.eparent.com/adinfo



Discover the faces of Children's Hospital

Everyday we take special care of children. From broken bones to long-term care, from infants to teens. It's our understanding of children and their families that makes us unique.

For over 80 years now, Richmond's Children's Hospital has been providing specialty pediatric care. We understand children. And what it takes to tailor our services to their individual needs.

Take for example, our Pediatric Feeding Disorders Program, one of only a few such services in the country.

Or our Inpatient Rehabilitation Program which helps children who have experienced trauma, disease or impairments return to the activities of daily life.

For adolescents who need subacute care to babies who have never seen the outside world, our Transitional Care Unit is a step toward home. And a place where parents learn to care for their child's special needs.

Discover where children come first.

Children's Hospital
Specialty Services for Children

2924 Brook Road • Richmond, Virginia 23220-1298
(804) 228-5818
www.childrenshosp-richmond.org

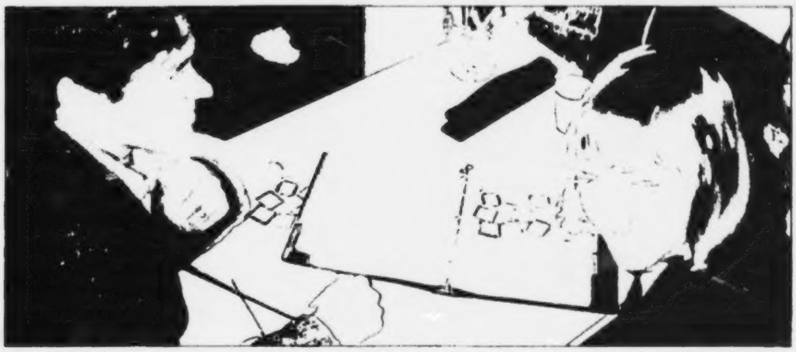
We accept most commercial payors, Medicaid HMO's and Medicaid.

Circle #26 or visit www.eparent.com/adinfo

contents

MAY 2002 • VOLUME 32, ISSUE 5

TRANSITIONING



SPECIAL REPORT:
44 UPDATE ON THE TREATMENT OF CHILDHOOD MOVEMENT DISORDERS
by Anne Kirkland
Taking a closer look at treatments for movement disorders.

58 Positive Behavioral Supports for Young Adults
by Julie Fodor, PhD, Kimberly Brown Campbell, MA, and Celia Flinn, MEd
Meeting behavioral challenges in community-based settings.

70 Understanding Transition Services
by Gretchen L. Jefferson, PhD, and Robert F. Putnam, PhD
A parent's guide to legal standards and effective practices.

92 Legislative Update
Ticket to Work program gets down to business.

106 Gynecological and Reproductive Healthcare for Women with Special Needs
by Catharine A. Kopac, PhD, GNP
Results of a study on gynecological services available for women with disabilities as reported by nurses.

FEATURES

26 Citizen Circle K: Corporate commitment to people with disabilities
by Paul T. Burke
How one corporation has made a commitment to helping people with disabilities through partnership with United Cerebral Palsy.

28 The Surgeon General on Health and Mental Retardation
by Duane Alexander, MD
Advising people with disabilities on health and community living.

78 Research Reflections Hooray for Hollywood...
by Jan Blacher, PhD
Upcoming Hollywood film *Pumpkin* confronts sexuality and developmental disability.

102 Orthodontic Care for the Person with Special Needs: An Overview
by Michael B. Koidin, DDS, MScD
Why people with disabilities should be assessed and treated for orthodontic needs.

BEST COPY AVAILABLE

COVER: The Cugini family, Rob, Eve, Nick, age 11, and Alex, age 5, of Houston, TX, tell their story this month in *Special Report: Update on the Treatment of Childhood Movement Disorders* (pg. 44). When he was 8, Nick underwent surgery to receive an ITB pump to treat the spasticity caused by his cerebral palsy.

EP
Exceptional Parent

contents

The Special Report *Update on the Treatment of Childhood Movement Disorders* is funded in part by an educational grant from Medtronics, Inc.

DEPARTMENTS

10 **Editor's Desk**

15 **Search & Respond**

22 **Letters**

82 **Special Section: Van Conversions**

89 **What's Happening**
- National Sports Festival for the Disabled
- New EP and Child Health Monitor Partnership
- S.O.F.T. 2002 Conference

91 **Familiar Faces**

94 **Parent Perspective**
Reel Life
by Roseann Forziano

97 **Organizational Spotlight**
The National Disability Sports Alliance (NDSA)

104 **EP Library**

112 **New Products**

116 **Children's Page**
What I Love About Sarah
by Bridget Kramer

EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTH-CARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy Ed Corp., dba *EXCEPTIONAL PARENT Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy Ed Corp. *EXCEPTIONAL PARENT®* is a registered trademark of the Psy Ed Corp. **Postmaster:** Please send address changes to: *EXCEPTIONAL PARENT*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *EXCEPTIONAL PARENT*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *EXCEPTIONAL PARENT*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #1420542. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

EXCEPTIONAL PARENT neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
While hyperbaric oxygen is effective therapy in certain conditions it is currently considered an alternative therapy for CP and other "brain insult" conditions. Readers are advised to discuss the advisability of HBOT with their primary or specialty healthcare providers as well as to study the current literature.

—Rick Rader, MD

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

MITCHELL F. BRIN, MD, Vice President, Botox, Allergan, Irvine, CA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics, Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof. Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

HARILYN ROUSSO, ACSW, Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

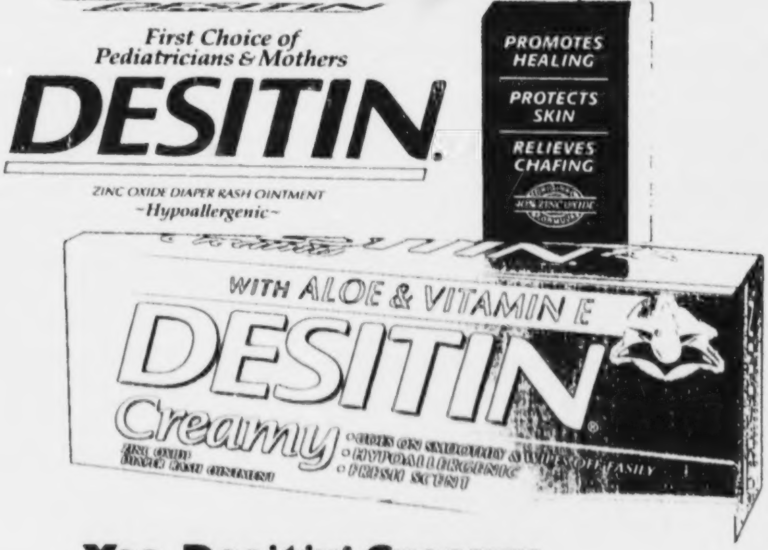
LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

THERESA VARNET, MSW, JD, Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

Does anything heal and protect precious little bottoms like Desitin®?


First Choice of Pediatricians & Mothers
DESITIN
ZINC OXIDE DIAPER RASH OINTMENT
~Hypoallergenic~
PROMOTES HEALING
PROTECTS SKIN
RELIEVES CHAFING
WITH ALOE & VITAMIN E
DESITIN
Creamy
ZINC OXIDE DIAPER RASH OINTMENT
GOES ON SMOOTHLY & WIPES OFF EASILY
HYPOALLERGENIC
FRESH SCENT

Yes, Desitin® Creamy.

Desitin Creamy was shown in a clinical study to work just like original Desitin. Plus, it's so creamy, it glides on smoothly and wipes off gently. Smells nice, too.

Desitin. More baby doctors choose it. More moms use it.

Circle #64 or visit www.eparent.com/adinfo

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Serving Adults having MR/DD

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #18 or visit www.eparent.com/adinfo

EP **EXCEPTIONAL PARENT MAGAZINE**

Information and Support for the Special Needs Community

EDITOR-IN-CHIEF	Rick Rader, MD
MEDICAL EDITOR & VP OF MEDICAL EDUCATION	Fern R. Potvin
MANAGING EDITOR	Natalie E. Gerber, PhD
EDITORIAL/MARKETING INTERN	Christina E. Spatz
EDITORIAL INTERN	Megan Henninger
INFORMATION SYSTEMS COORDINATOR	Dennis Dusevic
RESEARCH ASSISTANT	Susan Jenkins
GRAPHIC CONSULTANT	Dennis Wilkes
PRESIDENT, CEO & PUBLISHER	Joseph M. Valenzano, Jr.
VP BUSINESS DEVELOPMENT & INTERNET PROJECTS	Vanessa B. Ira
VP ORGANIZATION RELATIONS & CONSULTING EDITOR	Bridget M. Lyne
CHIEF FINANCIAL OFFICER	Dolores A. Kinley
AD TRAFFIC MANAGER	Kendra Kelly
SALES COORDINATOR	Doris DeFina
RECEPTIONIST/PUBLIC RELATIONS COORDINATOR	Robyn Sager
ART DIRECTION, DESIGN	Publishers Design Group, Inc. ✉annpdg@aol.com
PRODUCTION MANAGER	Michael Longobardi
EP LIBRARY	Ron Richards (800) 535-1910 ✉eplibrary@aol.com
WEBMASTER	Ken Fleischer, Dynamic Media Works ✉webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Jared F. Adams
EASTERN REGION:
(CT, ME, NH, NJ, NY, RI, VT)
✉jadams@eparent.com
(201) 489-4111,
Fax: (201) 489-0074

Barbara Nastro
SOUTHEAST REGION:
(AL, AR, DC, DE, GA, FL, MD, MS, NC, PA, SC, VA, WV)
SCHOOLS, CAMPS, RESIDENCES & CLASSIFIED
✉ nastro@blast.net
(908) 534-6366
Fax: (908) 534-6941

Annabelle and Gabe Jacobson
MIDWEST REGION:
(IA, IL, IN, KS, KY, MI, MN, MO, NE, ND, OH, OK, SD, TN, WI)
AUTOMOTIVE
The Lyon Group
✉ bellyon@megsinet.net
(847) 256-6850
Fax: (847) 256-6819

Larry Battistello
WESTERN REGION:
(AK, AZ, CA, CO, HI, ID, LA, MT, NM, NV, OR, TX, UT, WA, WY)
Marketing Plus
✉ seeme4ads@aol.com
(760) 320-8797
Fax: (760) 320-9728

Vanessa B. Ira
MASSACHUSETTS & INTERNET AD SALES
✉ vieprnt@concentric.net
(201) 489-4111, ext. 209
Fax: (201) 489-0074

COLOR SEPARATION/FILM PREPARATION
Plate Masters Inc., Carlstadt, NJ 07072

PUBLISHING & EDITORIAL OFFICE
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

SUBSCRIBER SERVICE:
EXCEPTIONAL PARENT
P.O. Box 2078, Marion, OH 43306-2178.

CUSTOMER SERVICE/NEW ORDERS:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

EXCEPTIONAL PARENT magazine was founded in 1971 by Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 98

"Discover" NEW Opportunities

Living Books

The Center for Discovery
DISCOVERY

The Center for Discovery is certified by New York State through the State Education Department, the Department of Health and the Office of Mental Retardation and Developmental Disabilities (OMRDD); and by the Commission on Accreditation of Rehabilitation Facilities (carf).

Visit us at our Booth at The World Congress & Exposition on Disabilities in Orlando, Florida – October 3-5, 2002

The Center for Discovery, a nationally-renowned prep school for children with significant disabilities (including multiple disabilities, medical frailties and some behavioral concerns) recently opened several new, small, universally-designed residences.

Located near Monticello, NY in the picturesque Catskill Mountains, just two hours northwest of New York City, The Center features a nature-based program that challenges children, and their families, to work with us to provide the finest educational, clinical, social and residential opportunities available anywhere.

We may just be the right program for your child.

Call our Admissions Office at (845) 794-1400, extension 1444 for information and/or to arrange a personal tour and see *discovery* in action.

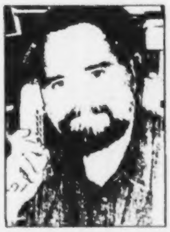
Ask for our new video.

Box 840 / Harris, NY 12742
845-794-1400, extension 1444
email: admiss@sdtc.org

Visit our websites:
www.thecenterfordiscovery.org
www.discoveryifi.org

BEST COPY AVAILABLE

"What Happened to You?" and Other Clinical Ice Breakers



There's an old vaudeville routine with a doctor asking his patient, "So tell me, Mr. Lawson, what brought you to my office today?" The patient replies "The number seven trolley, Doc, same as always." It probably wasn't funny even back at the Loews Brevoort.

Opening remarks, especially the first sentences of sonnets, declarations of war, great novels or examination room "lead-ins," are significant. There are books with compilations of the first sentences of great literature, presidential inaugural addresses, Oscar-winning acceptance speeches, half-time locker room sermons and Star Trek episodes, all attesting to the notion that "openings" are powerful thresholds to human transaction.

Medical school teaches "how to take a patient's history," but they don't teach you how to begin to take a patient's history. Popular spiral-bound manuals, lodged like marsupials in the pockets of students' white clinic coats, suggest "eliciting the presenting complaint." Fourth-year senior clinical clerks clutch index cards scrawled with "when did whatever is bothering you first start," an opening as inviting as the student snapping on a glove and spreading some lubricant on his fluttering index finger. The noted physician/educator Paul Hamilton Wood was fond of saying that "the best history taker is he who can best interpret the answer to a leading question." The doyen of medical education, Sir William Osler, hammered "ask the patient what's wrong, he wants to tell you." Two great axioms, for sure, but neither brings the novice to the most effective opening statement. There is a sparseness of literature that addresses the question "what to say after you appear and stop fidgeting with the stethoscope draped around your neck."

When the question is directed not to patients themselves, but to the parents (as in the case of so many EP readers), the stakes can be high. Opening lines reveal a lot about the physician and his/her attitudes, capacity for partnering, harmony, approach and flow. It's simple propulsive physics: ask the right question and you'll get the right answer (if there is such a thing). So what's the physician, counselor or therapist to start out with in order to get the dialogue going in a productive, revealing and comprehensive flow?

Dr. Ralph I. Horowitz, chairman of the Department of Internal Medicine at the Yale School of Medicine, recently addressed this very same question. The school conducted an interactive doctor/patient theatrical performance called "Rounding It Out," in the hope that physicians and medical students would gain an appreciation for this ritual. Conducting the program was Anna Deavere Smith, who has emerged as the premiere teacher in the art of listening. Smith has distinguished herself teaching listening skills to law students in addition to teaching performance studies and theater at major universities.

Dr. Horowitz remarked that "the most remarkable part of what took place was how little probing it took for her to hear stories from patients that we almost never hear." Horowitz offers that physicians by nature are disease-oriented, while Smith's role was to redirect the focus to be people-oriented.

Ms. Smith suggested the opening question below to get patients to share their stories—stories that are not disease-specific but reveal the nature of the disease and its impact, significance and meaning. These are the criteria that should send the physicians of tomorrow scurrying for their yellow highlighters. These are the things that make a history come alive and must be incorporated into a mutually agreed-upon plan of action.

"What happened to you?"

When was the last time a physician asked you that question? It's one of those pearls, those eurekas, those epiphanies. It's an invitation accompanied by a gesture that says "go on, I won't interrupt you." It's a question that smoothes the road ahead; it lets the patient and/or the parent know that the physician is prepared to hear the goods, to listen and learn. It's a question that a friend might pose to you after seeing how lousy you looked, that something assuredly had to have happened to you. Throw out that question, lean your body in the patient's (or parent's) direction as if what you're about to hear is the most important thing you have heard all day and then click on your seat belt. Chances are that you, the clinician, are in for the history-taking ride of your life. History taking is an art, one that requires a canvas, a palette and an astute eye. The parents, the patients, will supply the canvas and the palette; the rest is up to the physician.

Karen W. Arenson, in an article about Smith in the New York Times (Education Life, 13 January 2002), reports that "a linguist once told [Smith] there are three questions that will get anyone talking: What were the circumstances of your birth? Have you ever come close to death? Have you ever been accused of something you didn't do?"

My revised list of the three questions that will always get an exceptional parent talking are:

"When did you first notice something was wrong with your child? What has been your greatest frustration in dealing with the 'system'? and What is your single greatest wish for your child?"

Pose one of those questions to parents of a child with special healthcare needs—heck, you can even forgo leaning your body toward them—and you will get an earful. An earful made up not of mere words, but of ongoing sagas; not polished recitations, but heartfelt recollections that are subject to change with each telling. Storytelling from storytellers who want to be heard. Exceptional stories, extraordinary histories, incredible recountings. Ask an exceptional parent "what happened" and you will not only hear what happened; you can bank on hearing what's happening now and what's gonna happen next, because one thing is sure of EPers. While they may be stunned at times, they're but moments away from calculating their next steps, their next moves.

My revision to Smith's "magic bullet" opening question is: don't ask an exceptional parent "what happened to you?"; rather, simply ask "what have you made happen?" EP

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

EP Exceptional Parent

EXCEPTIONAL PARENT *presents* FREE

"Ask the Expert"

Teleconference and Web Seminar

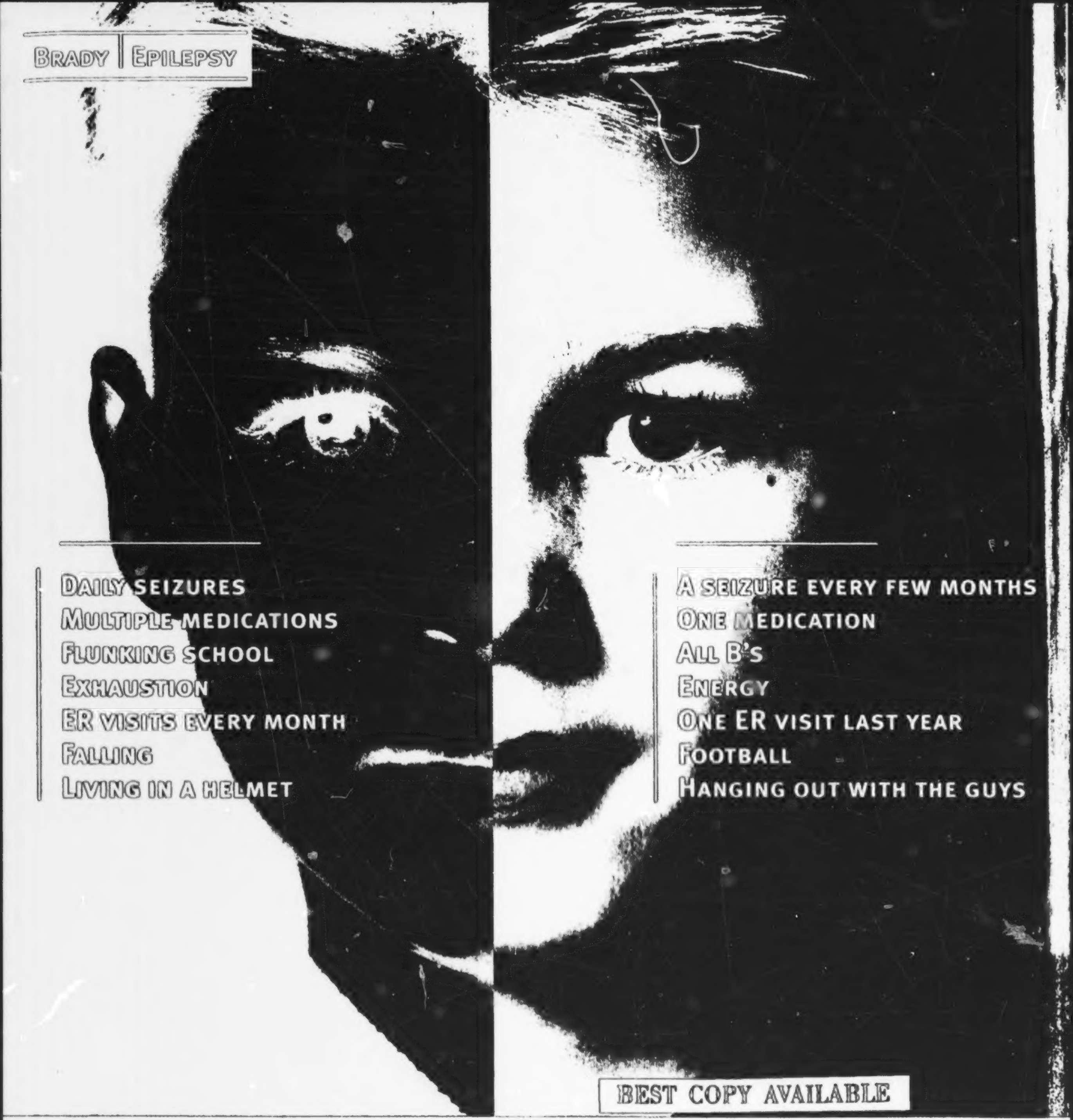
Diagnosing and Treating Childhood Movement Disorders

Faculty:
A. Leland Albright, MD, Professor of Neurosurgery, University of Pittsburgh School of Medicine; Chief, Department of Pediatric Neurosurgery, Children's Hospital of Pittsburgh
Terence S. Edgar, MD, Associate Professor of Neurology and Pediatrics, University of Arkansas Medical School; Director of Neuromuscular and Movement Disorders Programs, Arkansas Children's Hospital

June 26, 2002 • 6 PM – 7 PM (EDT)
July 10, 2002 • 8 PM – 9 PM (EDT)

For additional information and instructions about access, please see the ad on page 56.

SPONSORED IN PART BY AN EDUCATIONAL GRANT FROM MEDTRONIC, INC.


BRADY | EPILEPSY
DAILY SEIZURES
MULTIPLE MEDICATIONS
FLUNKING SCHOOL
EXHAUSTION
ER VISITS EVERY MONTH
FALLING
LIVING IN A HELMET
A SEIZURE EVERY FEW MONTHS
ONE MEDICATION
ALL B'S
ENERGY
ONE ER VISIT LAST YEAR
FOOTBALL
HANGING OUT WITH THE GUYS

BEST COPY AVAILABLE

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

BEST COPY AVAILABLE

VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS THERAPY™

VAGUS NERVE STIMULATION

Cyberonics

Circle #32 or visit www.eparent.com/adinfo

EXECUTIVE SUMMARY[1]
SAFETY INFORMATION
FOR THE NCP® SYSTEM

INTENDED USE / INDICATIONS – UNITED STATES

The NCP System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures which are refractory to antiepileptic medications.

CONTRAINDICATIONS

- The NCP System cannot be used in patients after a bilateral or left cervical vagotomy.
- Do not use short-wave diathermy, microwave diathermy, or therapeutic ultrasound diathermy on patients implanted with the NCP System. Diagnostic ultrasound is not included in this contraindication.

WARNINGS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals. This is not intended to serve as a substitute for the complete NCP System Physician's Manual.

The **safety and efficacy** of the NCP System has not been established for uses not covered in the "Intended Use/ Indications" section of the manual.

The safety and efficacy of the NCP System treatment has not been established for stimulation of the **right vagus nerve** or of any other nerve, muscle, or tissue.

Excessive stimulation at a combination of high frequency (≥ 50 Hz) and an excess duty cycle (that is, one that occurs when ON time is greater than OFF time) has resulted in degenerative nerve damage in laboratory animals. An excess duty cycle can be produced by continuous or frequent magnet activation (> 8 hours), as determined by animal studies. Cyberonics recommends against stimulation at these combinations of ranges.

Aspiration may result from the increased swallowing difficulties reported by some patients during stimulation. Patients who have **pre-existing swallowing difficulties** are at greater risk for aspiration.

Device malfunction could cause painful stimulation or direct current stimulation. Either event could cause nerve damage and other associated problems. Patients should be instructed to use the magnet to stop stimulation if they suspect a malfunction, and then to contact their physician immediately for further evaluation. Prompt surgical intervention may be required if a malfunction occurs.

Susceptible patients with predisposed cardiac conduction systems (re-entry pathway) have not been studied as part of controlled clinical trials to establish the safety of NCP system treatment in these patients. Evaluation by a cardiologist is recommended if the family history, patient history, or electrocardiogram suggests an abnormal cardiac conduction pathway. Serum electrolytes, magnesium, and calcium should be documented before implantation. Post-implant electrocardiograms and Holter monitoring are recommended if clinically indicated.

Sudden unexplained death in epilepsy (SUDEP): Through August 1996, 10 sudden and unexplained deaths (definite, probable, and possible) were recorded among the 1,000 patients implanted and treated with the NCP device. During this period, these patients had accumulated 2,017 patient-years of exposure. Some of these deaths could represent seizure-related deaths in which the seizure was not observed, at night, for example. This number represents an incidence of 5.0 definite, probable, and possible SUDEP deaths per 1,000 patient-years. Although this rate exceeds that expected in a healthy (nonepileptic) population matched for age and sex, it is within the range of estimates for epilepsy patients not receiving vagus nerve stimulation, ranging from 1.3 SUDEP deaths for the general population of patients with epilepsy, to 3.5 (for definite and probable) for a recently studied antiepileptic drug (AED) clinical trial population similar to the NCP System clinical cohort, to 9.3 for patients with partial onset epilepsy.

The NCP device is not curative: Physicians should warn patients that the NCP System is not a cure for epilepsy and that since seizures may occur unexpectedly, patients should consult with a physician before engaging in un-supervised activities, such as driving, swimming, and bathing, and in strenuous sports that could harm them or others.

Obstructive Sleep Apnea: Patients with obstructive sleep apnea (OSA) may have increased apneic events during stimulation. Cyberonics recommends care when treating patients with preexisting OSA. Lowering stimulus frequency or prolonging OFF time may prevent exacerbation of OSA.

PRECAUTIONS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals.

Laryngeal irritation may result from stimulation. **Patients who smoke** may have an increased risk of laryngeal irritation.

Dyspnea may result from stimulation. **Patients with chronic obstructive pulmonary disease** may have an increased risk of dyspnea.

It is important to follow **recommended implantation procedures and intraoperative product testing** described in this manual. During the intraoperative Lead Test, rare incidents of bradycardia and/or asystole have occurred. As of October 1998, approximately 3,000 patients had been implanted with the NCP System. Four of these patients were reported to have experienced **bradycardia and/or asystole** during the intraoperative Lead Test. All four patients recovered without sequelae. One of the four patients was implanted with the NCP System. There were no postoperative or VNS-treatment-related cardiac adverse events later reported for that patient. No similar events were reported to have occurred during the clinical studies at the time of implantation or during treatment. The safety of this therapy has not been systematically established for patients experiencing bradycardia or asystole during NCP System implantation.

Reversal of lead polarity has been associated with an increased chance of bradycardia in animal studies. It is important to make sure that the Lead connector pins are correctly inserted (white marker to + connection) into the Pulse Generator header.

It is important to follow **infection control procedures**. Infections related to any implanted device are difficult to treat and may require that the device be explanted. Cyberonics recommends that the patient be given antibiotics preoperatively. The surgeon should ensure that all instruments, including the NCP Tunneling Tool, are sterile prior to the operation.

The NCP System is indicated for use only in stimulating the **left vagus nerve** in the neck area inside the carotid sheath.

The NCP System is indicated for use only in stimulating the **left vagus nerve below where the superior and inferior cervical cardiac branches separate from the vagus nerve.**

A neck brace can be used by the patient for the first week to help ensure proper Bipolar Lead stabilization.

Environmental and Medical Therapy Hazards

Patients should exercise reasonable caution in avoiding devices that generate a **strong electric or magnetic field.** (For examples, see the "Other Environmental Hazards" section of the Physician's Manual.) If a Pulse Generator ceases operation while in the presence of electromagnetic interference (EMI), moving away from the source may allow it to return to its normal mode of operation.

NCP System operation **should always be checked** by performing device diagnostics after any of the procedures mentioned in the Physician's Manual.

Because of where the Pulse Generator is implanted in the chest, **patients may need to be specially positioned in mammography equipment for clear imaging.** Otherwise, the device may be seen as a shadow on the mammogram. (Most routine diagnostic procedures, such as fluoroscopy and x-radiography, are not expected to affect system operation.)

Therapeutic radiation may damage the Pulse Generator's circuitry, although no testing has been done to date and no definite information on radiation effects is available. Sources of such radiation include therapeutic x-rays, cobalt machines, and linear accelerators. The radiation effect is cumulative, with the total dosage determining the extent of damage. The effects of exposure to such radiation can range from a temporary disturbance to permanent damage, and may not be detectable immediately.

External defibrillation may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for external defibrillation.

Electrocautery surgery may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for electrocautery surgery.

Magnetic resonance imaging (MRI) should not be performed with a magnetic resonance body coil in the transmit mode. The heat induced in the Bipolar Lead by an MRI body scan can cause injury.

Use caution when other MRI systems are used, since adverse events may occur because of different magnetic field distributions.

No scan in which the radiofrequency (RF) is transmitted by the body coil should be done on a patient who has the NCP System. Thus, protocols must not be used which utilize local coils that are RF-receive only, with RF-transmit performed by the body coil. Note that some RF head coils are receive only, and that most other local coils, such as knee and spinal coils, are also RF-receive only. **These coils must not be used in patients with the NCP System.**

Therapeutic ultrasound. Routine therapeutic ultrasound could damage the Pulse Generator and may be inadvertently concentrated by the device, causing harm to the patient.

Extracorporeal shockwave lithotripsy may damage the Pulse Generator. If therapeutic ultrasound therapy is required, avoid positioning the Pulse Generator part of the body in the water bath or in any other position that would expose it to ultrasound therapy. If that positioning cannot be avoided, program the Pulse Generator output to 0 mA for the treatment, and then after therapy, reprogram the Pulse Generator to the original parameters.

Diagnostic ultrasound is not expected to affect the NCP System.

The Pulse Generator may affect the operation of **other implanted devices,** such as cardiac pacemakers and implantable defibrillators. Possible effects include sensing problems and inappropriate Pulse Generator responses. If the Pulse Generator patient requires concurrent implantable pacemaker and/or defibrillator therapy, careful programming of each system is necessary to optimize the patient's benefit from each device.

ADVERSE EVENTS

Adverse events reported during clinical studies as statistically significant are listed in alphabetical order Ataxia (muscle movements or twitching, generally associated with stimulation); Dyspepsia (indigestion); Dyspnea (difficulty breathing, shortness of breath); Hypesthesia (impaired sense of touch); Increased coughing; Infection; Insomnia (inability to sleep); Laryngismus (throat, larnx spasms); Nausea; Pain; Paresthesia (prickling of the skin); Pharyngitis (inflammation of the pharnyx, throat); Voice alteration (hoarseness);Vomiting.

Other potential adverse events possibly associated with surgery or stimulation include but are not limited to the following:

Aspiration (fluid in the lungs); Blood clotting; Choking sensation; Damage to nerves or vasculature in the surgical area, including the carotid artery and jugular vein; Device (Generator and/or Lead) migration or extrusion; Dizziness; Dysphagia (difficulty swallowing); Duodenal ulcer, gastric ulcer; Ear pain; Facial flushing; Facial paralysis, paresis; Foreign body reaction to implants, including possible tumor formation; Formation of fibrous tissue, pockets of fluid; Heart rate and rhythm changes; Hiccuping; Incision site pain; Irritability; Laryngeal irritation (sore, painful throat); Left hemidiaphragm paralysis; Left recurrent laryngeal nerve injury; Left vocal cord paralysis; Low-grade fever; Muscle pain; Neck pain; Nerve injury; Painful or irregular stimulation; Skin, tissue reaction; Stomach discomfort; Tinnitus (ringing in the ears); Tooth pain; Unusual scarring at the incision site; Urinary retention; Vagus nerve paralysis; Weight change; Worsening of asthma and bronchitis; Worsening of cardiac abnormalities, including heart rate and rhythm.

Patients who manipulate the Pulse Generator and Bipolar Lead through the skin may damage or disconnect the Bipolar Lead from the Pulse Generator and/or possibly cause damage to the vagus nerve.

---

[1] The information contained in this Executive Summary for Physicians represents partial excerpts of important prescribing information taken from the *NCP Pulse Generator Physician's Manual*. The information is not intended to serve as a substitute for a complete and through understanding of the material presented in all of the Physician Manuals for the NCP System and its component parts nor does this information represent full disclosure of all pertinent information concerning the use of this product, potential safety complications, or efficacy outcomes.

Search & Respond

S

Huntington prognosis

I am the mother of two boys, ages 10 and 8 years, who have been diagnosed with Huntington disease. It was inherited from their father's family. Recently, their father told me that he is now showing signs of the disease, which has killed his brother, mother and grandfather. My 10-year-old is at an early second grade level and the 8-year-old is the same but going down hill. Both boys are very loving and happy all the time, but tire easily when playing with other kids. I would like to hear the experiences of other parents of children with HD so I may know about what to expect in the future.

—89 via EP Web site

Editor's Note: The Huntington Disease Society of America is a resource for information and advocacy. Their Web site can be accessed at: http://www.hdsa.org/

S

Elevated lactic acid levels with brain abnormality

My 16-month-old son has a developmental brain abnormality (polymicrogyria, pachygyria, and demylination of the white matter). There are other children with this but he also has elevated lactic acid levels. He also has microcephaly and is developmentally delayed in all areas. I'm searching for someone who has the diagnosis that my son has so I have some idea of what to expect of prognosis. We have been recommended to go for a mitochondrial work-up. One of our questions is, will the lactic acidemia have an effect on him?

—E.L. via EP Web site

S

College for a child with ADHD/LD

My son is 18 and a senior in high school. He has ADHD and an auditory integration problem. He has struggled to have a grade-point average acceptable to most colleges, but his ACT scores are strong enough to go to college. Are there any colleges or universities that address learning disabilities and really offer students the help they need to get through college? We have been working toward independence in study, but our son is still not there yet.

—M.S. via EP Web site

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our Web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

EP PROUDLY ANNOUNCES TWO NEW COLUMNS! TECH TALK & SPORTS CORNER

Beginning in the June issue, EP will introduce two new occasional columns, *Tech Talk* and *Sports Corner*. *Tech Talk* will address practical ways to integrate technology into educational, work and home environments. *Sports Corner* will cover adaptive sports, recreation and fitness. Readers will have the opportunity to have their questions answered in these columns. E-mail your question to epedit@aol.com and indicate the name of the column in the subject line. Be sure to provide your city and state. Young readers should also include their age.

S

Kleeblattschadel syndrome

My 3-year-old daughter was born with Kleeblattschadel syndrome (cloverleaf skull syndrome). It is a severe form of craniosynostosis. She has had many surgeries since she has been born. She also has a trach tube for airway, because her mid-face is compacted and will need surgeries in the future. She is my only child. She has had genetic testing, but so far they do not know how this happened or why. I was wondering if anyone has been through this and if they have any other children who were born without disabilities.

—267 via EP Web site

S

Agenesis of the corpus callosum

I am writing looking for information

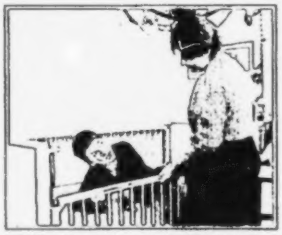
continued on page 19

HARD MANUFACTURING

AGE APPROPRIATE BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas



The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs, as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #45 or visit www.eparent.com/adinfo

Search & Respond

continued from page 15

on treatment or therapies for agenesis of the corpus callosum (ACC). My daughter, who is 5 years old was diagnosed with ACC at age of 2. I currently have her in Early Intervention, where she receives speech, physical and occupational therapies. Her neurologist has diagnosed her as having mild retardation and autism. She can walk, but no running, jumping, or climbing. She will sometimes feed herself finger food. She has no verbal skills. She has been treated for strabismus, and although children with ACC are sometimes prone to seizures, I have not seen any yet. Children with this disorder seem so different from one another, ranging in how severely they are affected by ACC. My daughter has made very little progress in many areas, and the majority of people who work with her, myself included, are very frustrated by how little information is out there to work with her and get through to her. I know my daughter is very frustrated, like she is trapped.

At times she looks like she understands what is being said to her, but she cannot act on it. At times she makes progress and then takes several steps backwards. I wish I knew how to find the key to be able to open that door. If there is any information on where I can look, I would be very grateful. We have already contacted the ACC Network, and gotten information from several Web sites.

—G. Wortmann via EP Web site

Instant S&R

Catheterization in spina bifida: timed vs. ultrasound-based

I am a physician assistant in family practice. I have a patient with spina bifida who has an "Indiana pouch" to provide urinary continence. He "self-caths" on a scheduled basis and has chronic bacteriuria (bacteria in his urine). His urine cultures are almost invariably "swarming" with Proteus mirabilis or E. coli. I am concerned that the repeated self-cath contributes to the bacteriuria and multiple urinary tract infections. I approached his urologist about changing to ultrasound based catheterization but she adamantly refused this, informing me that this could worsen his urinary tract problems and even contribute to reflux and kidney damage. I assume that she is right but I would be extremely grateful to hear from anyone with experience in this area.

—150 via EP Web site

Maybe the problem is something simpler. Many individuals with spina bifida display allergies to latex among others. Is the catheter latex? Another option would be to use "diapers" which the individual changes himself. This has cleared up infection problems with others.

—184 via EP Web site

continued on page 20

Corrections:

The individual authors of the article "Effective Social Skills Programming" in the February 2002 issue are Robert F. Putnam, PhD, and Jannette Rey, PhD. Drs. Putnam and Rey provide consultation services at the May Institute (www.mayinstitute.org).

THE MELMARK SCHOOL

2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

Our approved private day and boarding school serves children ages 5-21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Acquired Brain Injuries
- Cerebral Palsy
- Mental Retardation
- Neurological Disorders

We Offer Your Child:

- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK Ext. 636 or email admissions@melmark.org

Circle #60 or visit www.eparent.com/adinfo

Adaptivemall.com™

Shop On-line!

Tim's daughter Carrie.. a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.
Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie

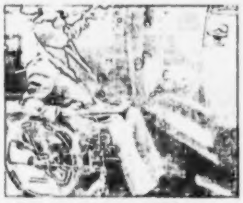
Tumble Forms is a trademark of Sammons Preston

Copyright 2001 Bergeron Health Care

Circle #22 or visit www.eparent.com/adinfo

DRIVE-MASTER

50 YEARS of Providing Mobility for the Physically Challenged



STEERING YOU IN THE RIGHT DIRECTION

Innovators Then...

Partial Features Include...
- Hand Controls
- Reduced Effort Steering
- Reduced Effort Braking
- Foot Steering
- Left Foot Gas Pedals
- Wheelchair Lifts
- Porch Lifts
- Steering Devices
- Backup Brakes & Steering
- Horizontal Steering
- Complete Van Conversions
- Block Pedal Extensions

And Much More!
For additional info.
contact Drive-Master

Experts NOW!

DRIVE MASTER

9 Spielman Road, Fairfield, NJ 07004-3403
Phone: (973) 808-9709 • Fax: (973) 808-9713
E-mail: drivemaster@drivemaster.net
Web: www.drivemaster.net

24 HOUR TURNAROUND SERVICE

MEMBER

Circle #33 or visit www.eparent.com/adinfo

continued from page 19

Respond

Holding a child back in school

HB (March 2002) has a son with developmental delay and wants to know the advantages (or disadvantages) of holding him back in school.

Our son is now 12 years old and in the fifth grade. When we moved from California to Connecticut, we had him repeat the second grade, feeling strongly at the time that he simply would have been "swallowed up" in third grade. Today, we know we made the right decision. David has been diagnosed with NLD/Asperber traits and is small and socially immature. He also has some difficulty with math and reading comprehension.

Holding David back has given him a little extra time to grow—something more people should consider instead of rushing their kids through school.

The only disadvantage is your child will be one of the oldest in the class—something which is really no big deal at all.

Follow your heart and do what you feel is right for your son.

—K.E., Connecticut

Support Group for Tetrasomy or Pentasomy X

Tetra-x-list (http://www.tetra-x-list@yahoogroups.com) is an online listserv support group serving families and individuals dealing with tetrasomy or pentasomy X (as well as triple X/tetra X and tetra X/penta X). The group also links families who do not have access to e-mail by keeping a database of addresses. In existence since February 2000, Tetra-x-list has 50 online group members and 20 additional offline.

The goal for Tetra-x-list is to provide support, share information about these disorders, provide links to other local resources, identify and help as many people as possible with the disorders, and eventually support more research on the syndromes. The group will also provide help to families who aren't interested in joining.

For more information, contact:
Cyndi Bradley
1402 Governor House Circle, Wilmington, DE 19809
Phone: (302) 764-3924
E-mail: Cyndibradley@hotmail.com
http://www.tetra-x-list@yahoogroups.com.

546

Sally, 40 lbs. and 45" tall, in the #8600 Reclining Bath Chair with #8875 Head Pad

Sharing the Caring

BEST COPY AVAILABLE

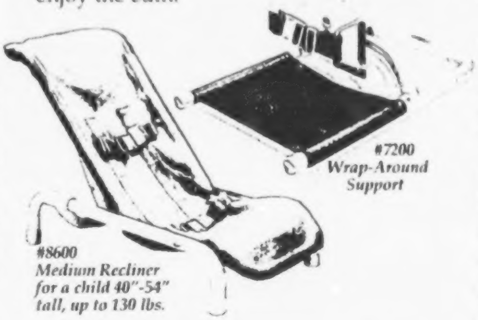
Columbia offers you solutions to the daily challenges of bathing, toileting and transporting your child – *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

☐ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.

#5800 Hi-Back Positioning Commode for junior adults

☐ At bathtime, our popular **Wrap-Around Bath Supports** and **Reclining Chairs** allow your child – and you – to enjoy the bath.



#7200 Wrap-Around Support

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

☐ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.–yet weighs only 11 pounds! Comfort, style and adjustability have made it the No. 1 choice since 1986.

#2000 Car Seat

Why do these products work so well?

Much thought and care go into the design of each Columbia product. We make each item in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, proven in real life. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

COLUMBIA
SHARING THE CARING

Circle #27 or visit www.eparent.com/adinfo

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG

Columbia Medical Mfg. Corp., Dept D2, P.O. Box 633, Pacific Palisades, CA 90272
Visit our web site at http://www.ColumbiaMedical.com

UCP FOUNDATION REPORT ON OXYGENATION RAISES COMMENT

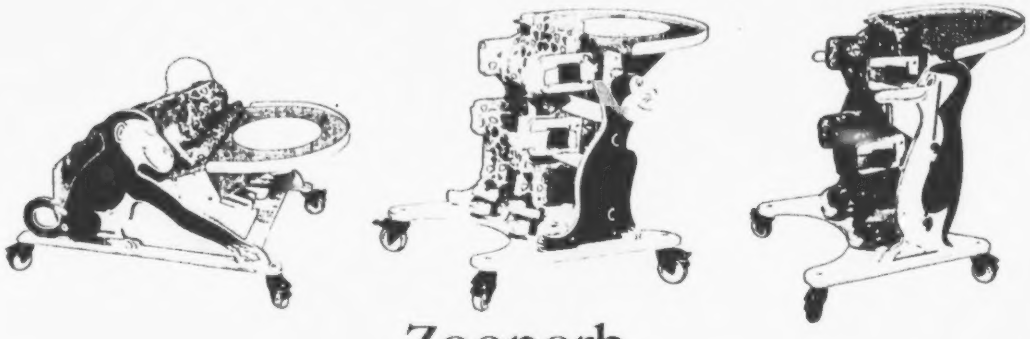
To the Editor: I want to commend you on printing the UCP Foundation Report on the potential role of oxygenation therapy in the treatment of brain injury (March 2002, pgs.64-65). This is a very comprehensive report and excellent information is made available. I would like, however, to comment on some of the statements made.

There was a suggestion that idling neurons in the brain are somewhat of a fantasy. This concept has been well-documented in the literature by Astrup, et. al., in Stroke in 1981, wherein the ischemic penumbra was first described. This was further documented clinically in an article published in The Lancet in 1990 and is well-known in academic medicine in neurology. Certainly, dormant idling neurons may recover spontaneously, as the rare patient may awaken from coma after a number of years; such a patient certainly did not grow new brain cells. The single photon emission computerized tomography (SPECT) scan, although mentioned not to be a metabolic imaging process, is metabolic because the tracer crosses the blood brain barrier. The PET imaging is excellent, extremely expensive, and not routinely covered by insurance for neurological problems. We have done both PET and SPECT and find a marked similarity.

The article also states that the McGill results were identical utilizing 1.75 ATA (atmospheres) 100 percent oxygen and 1.35 ATA air. I have discussed this fully with Dr. Pierre Marois, the chief investigator. The more serious cases were in the oxygen group and responded much faster than any of the cases in the air group. This does not mean, however, that 1.35 ATA air may not play a significant role in the treatment of cerebral palsy and brain injuries in the future. This observation is synchronous. Consider the hundreds of thousands of children who could never get to, or afford, a hyperbaric chamber. To pressurize a schoolroom at 1.35 ATA for one hour, twice a day, is a very reasonable, simple phenomenon. There are no explosions or ear problems. This is a remarkable finding and it should be explored.

I am very pleased to see that the UCP Research Education Foundation is attempting to make arrangements to investigate further the use of hyperbaric oxygenation and, possibly, pressurized air, which boosts the oxygen content to 27 percent. It is obvious that plain oxygen, per se, is of little value since it has been around for years and its use either by canula or mask has not made a great

We encourage letters on any subject. Send them to: EP Magazine, Attn: Letter to the Editor, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com. Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified by full name and state. Please include your phone number and/or e-mail address on all correspondence in case we need to contact you directly.



Zooperb.

Kids love the Monkeys, Cats, Penguins, and other creatures in this line of unique and extraordinary therapeutic equipment.

Distributed exclusively by Bodypoint Designs, Jenx™ has created a revolution in the evolution of children's positioning therapy. These new "species" of superb therapeutic tools help children stand, enhancing play and interaction with their peers. Designed for children aged 9 months to 7 years, they bring the support needed to their bodies, as well as a smile to their souls.

So, next time you need to position a child for success, introduce them to Jenx. Zooperb in every way.

JENX
Distributed by
BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104
In Canada, call Advanced Health Care Products, Tel: 800-265-9830

Circle #24 or visit www.eparent.com/adinfo

impact in the treatment of these young children except in very acute phases where surface oxygen has proven invaluable.

An article by Dr. Zarabeth Golden, et. al., in the International Journal of Neuroscience, "Improvement in Cerebral Metabolism in Chronic Brain Injury after Hyperbaric Oxygen Therapy", expresses improvement in cerebral metabolism in chronic brain injury after hyperbaric oxygenation therapy. This represents a statistical analysis of changes in blood flow and metabolism in the clinical setting. There is an 85 percent correlation between these changes and the patient's overall neurological status.

According to stringent US scientific standards, double-blind crossover control studies are mandatory before something becomes acceptable. I need to point out that only 17 percent of all Medicare and insurance-reimbursable conditions have been so studied. Appendectomy, coronary bypass surgery, penicillin, lumpectomy in breasts and many surgical procedures have never been studied in this fashion. Certainly, further investigation of hyperbaric oxygenation for cerebral palsy and brain injuries is warranted, but in no way should the potential improvement of any child be jeopardized for the sake of science.

Richard A. Neubauer, MD, Medical Director
Ocean Hyperbaric Neurologic Center,
Lauderdale-by-the Sea, FL

"NOTICEABLE DIFFERENCE" GAINS NOTICE

To the Editor: "On Noticing A Noticeable Difference" (Editor's Desk Feb. 2002) was an excellent editorial! The frustration with pediatricians who dismiss parents' concerns about their child's development is widespread.

In my own experience, my pediatrician repeatedly dismissed my concerns about my child's delays for more than two years. When my son hadn't started to talk by age 30 months, all that was suggested was a hearing test. It turned out he had autism. If the pediatrician hadn't been so quick to dismiss my repeated concerns, my son could have started early intervention at a younger age, which might have helped him develop to his full potential.

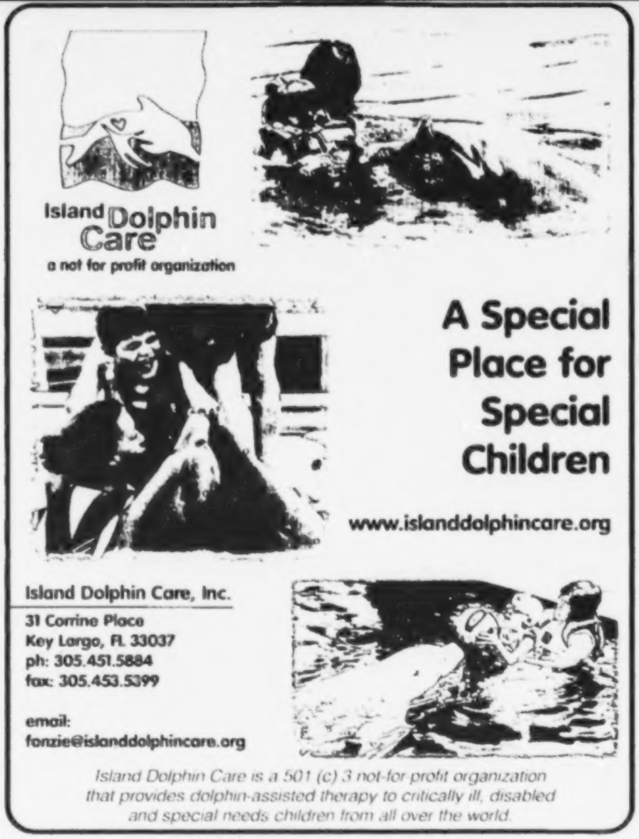
Some delays may be safely dismissed, but I don't see any harm in doctors' ordering tests. If things turn out normal, fine. If not, early intervention can have lifelong benefits for the child. The "let's wait and see" or "let's take a look at that in six months" approach seems outdated in today's society when there are so many resources available to children with disabilities. These resources need to be applied as early as possible in the child's life to provide the greatest benefit.

Mary Shewan

RESPONSE TO ARTICLE ON "WHAT'S WRONG WITH TIMMY?"

To The Editor: After reading every other article in the November 2001 EP ("It All Begins in the Home," pgs. 60-61), I finally mustered up the courage to read the story about Maria Shriver and her new book, What's Wrong with Timmy? I am not proud to say it, but I have been angry with Maria Shriver since her book came out. Why? I saw a portion of her interview with Tim Russert on CNBC in which she

continued on page 24


Island Dolphin Care
a not for profit organization

A Special Place for Special Children

www.islanddolphincare.org

Island Dolphin Care, Inc.
31 Corrine Place
Key Largo, FL 33037
ph: 305.451.5884
fax: 305.453.5399

email:
fonzie@islanddolphincare.org

Island Dolphin Care is a 501 (c) 3 not-for-profit organization that provides dolphin-assisted therapy to critically ill, disabled and special needs children from all over the world.

Circle #52 or visit www.eparent.com/adinfo

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at
DISCOUNT PRICES!

As a service to our customers, we offer **FREE SAMPLES** of disposable youth briefs and pull ups.

Save up to 50%
Call **1 800 777 1111** 24Hrs
WOODBURY PRODUCTS, INC.
Order online at: **www.woodburyproducts.com**

Circle #79 or visit www.eparent.com/adinfo
GoodNites
GoodNites
GoodNites

The BEST strollers in the WORLD!
by Baby Jogger
Our Special Needs strollers are lightweight, easy to fold, and a joy to push...
BABY JOGGER
www.babyjogger.com • (509) 457-0925

Circle #72 or visit www.eparent.com/adinfo

Hyperbaric Oxygen Therapy [HBOT] is the breathing of 100% oxygen under increased atmospheric pressure. The effects of HBOT on the organs and tissues of the body are multi faceted.*

South Florida Center for H.O.P.E. offers a clean and bright friendly atmosphere, using only state-of-the-art equipment. Our doctors and technicians are trained by a UHMS accredited course and certified in HBOT by the NBDHMT. They come with many years experience in the field of hyperbaric medicine.

* Hyperbaric Medicine Practice
Eric P. Kindwall, M.D.

WE OFFER **H.O.P.E.**
[HYPERBARIC OXYGEN PRODUCING ENVIRONMENT]

CONDITIONS TREATED WITH HBOT
- *CEREBRAL PALSY [CP]*
- *TRAUMATIC BRAIN INJURY*
- *ANOXIC ISCHEMIC ENCEPHALOPATHY (AIE)*
- *NEAR DROWNING*
- *STROKE [CVA]*
- *MULTIPLE SCLEROSIS [MS]*
- *NON-HEALING WOUNDS**
- *RADIATION INJURY**
- *AUTISM*

* CURRENTLY APPROVED BY FDA

ANCILLARY SERVICES
- *INTEGRATED MANUAL THERAPY*
- *PHYSICAL THERAPY*
- *OCCUPATIONAL THERAPY*
- *SPEECH THERAPY*
- *BIO RESONANCE THERAPY*
- *NEURO-BIOFEEDBACK*

Dr. Ross Clark, M.D. Medical Director

South Florida Center for H.O.P.E
1898 H West Hillsboro Blvd.
Deerfield Beach, FL 33442
[954] 571-9392 Toll Free: [866] 473-HOPE

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #69 or visit www.eparent.com/adinfo

continued from page 23

talked about her book and why she wrote it. In the end, Tim and Maria both suggested that parents of children with special needs should be thankful for what they are given and love their children. This angered me greatly for several reasons. The first of which was: How dare they tell me what I should feel? Do they have a child with special needs? Are they driving numerous hours every week to take their child to physical, occupational and speech therapies? Do they have to travel to a different state to get care from a specialist? Do they have to keep a notebook full of various test results in order to give the doctor all the information needed? Do they have to be just as learned as their physician to ensure the best treatment for their child? Do they have a "normal" child who is jealous of her sibling's getting all the attention? Does that "normal" child feel she needs to wear a brace to be noticed, even when you think you have done everything in your power so she does not feel left out?

When we named our son Timothy, we did not know that he had special needs! We did not know that he had experienced a stroke during the first trimester of my pregnancy. And we didn't name him so that he could be compared to a character in a book.

I think the article about What's Wrong with Timmy is wonderfully written. I agree that "normal" children should play with special needs children. I am thankful for the schools' mainstreaming our special children with normal children. I am thankful for my son Timothy! I am angry, however, that I didn't know Timothy had a stroke while I carried him and that I could not help him. I am sad that he has to endure braces, therapy and botox injections. I am sad that he is self-conscious of his silly run, his stuttering and the fact that he is different from others. I am tired of people telling me how I should feel. And if one more person tells me that God does not give us more than we can handle—or some twist to that same phrase—so help me I will scream!

To steal a line from Ms. Shriver, "What is wrong with Timmy? Nothing, nothing at all!"

Gretchen Gibson, Jenks, OK

(The writer and her husband, Craig, are the parents of Timothy, Elizabeth and Miranda)

EDITOR'S NOTE: According to the transcript of Maria Shriver's interview on *The Tim Russert Show*, which aired on CNBC on October 20, 2001, Ms. Shriver said: "...Everybody you talk to, who talks about finding out about their child having a disability relays this kind of experience: the loss of dreams that they may have had for their child; the fear that's involved with this and then the learning to love the child that they actually have been given by God. And that's the challenge for all of us, as parents, is to love the child we have, not the child we think we wanted to have or the child we dreamed of having." Ms. Shriver has been very involved with the disabled community. Her mother, Eunice Kennedy Shriver, started the Special Olympics and has a sister with disabilities. Transcript courtesy of *The Tim Russert Show* on CNBC.

Informed Parents

Where Parents Keep Up To Date On Products For Their Children's Special Needs

The Gator Complete

GATOR

FUN Fact

All Supports From the Gator can be removed once the Walking Skills are Learned

Gator Standard
Comes with Adjustable Handle Bars, Bicycle Grips, Rear [illegible], and Anti Reverse Wheels with Caster Pin Locks.

When the Snug Seat product development team asked therapists and parents what they wanted in a gait trainer, they were told to concentrate on three areas.

Construct a product that will expand as the child grows - "this will save us money", Create a noise free product -"You can hear my child a mile away in other gait trainers", and use quality casters to make it easy to operate - "those tiny casters get caught in cracks and are difficult to maneuver over thresholds"

The revolutionary design of the Gator has allowed us to meet those objectives and many more. Our unique frame design provides built-in growth that requires the purchase of two competitive units. We are able to accomplish this feat with our unique width and height adjustable hand-grips and forearm supports.

Gator Complete
Shown with Arm Troughs, [illegible] Seat Ankle Supports, Pelvic Pad, and [illegible] Supports

The Gator's strong steel frame is made to last and eliminates the squeaks and creeks of competitive units, and our large swivel casters are easy to steer for even the most fragile child. We also provide caster pin locks as a standard feature.

Information/Free Catalog CD Rom
1-800-336-7684
snugseat.com

SNUG SEAT®

Circle #68 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

Citizen Circle K:

CORPORATE COMMITMENT to People With Disabilities

By Paul T. Burke

UCP
Understanding Disabilities Creating Opportunities

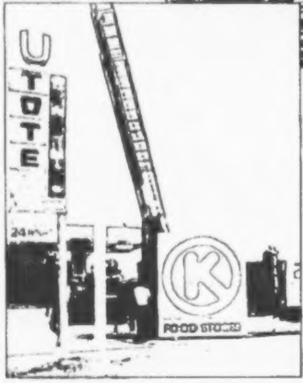
In the 1950s, America witnessed a phenomenon that it had not seen before in retail marketing – the advent of convenience stores. At first, these stores were open from early morning until just before midnight. They reflected the public's growing desire to be able to purchase basic commodities quickly and inexpensively in a highly mobile post-World War II society. Milk, soda, beer, coffee and cigarettes were the commodities in principal demand.

In many cases, the names associated with these convenience stores expressed the colorful diversity of America. In the Southwest, a chain of stores named Utotem was among the most popular. Like similar enterprises throughout the United States, this chain provided quick service to a mobile constituency in a hurry. In 1984, Utotem was purchased by Circle K, and its stores subsumed into a network of more than 2,400 convenience stores nationwide. Today, Circle K stores are also part of many Mobil Oil service stations on major highways.

Fast, friendly and clean stores were and remain a cornerstone for success. From the start, Customer Service Representatives (CSRs) learned to build rapport with customers who were in their stores for less than five minutes, seeking to make quick and inexpensive purchases from a multitude of categories. A cheery smile and helpful attitude—borrowed from a time when general stores served America—meant success in the convenience store business.

Good interpersonal skills translated into customer loyalty. Store managers also sought to establish their enterprises as places that made major contributions to the communities they served. The occasion of a customer being in a store for a short period of time with spare change from a recent purchase lent itself to an instant contribution opportunity. And so the Circle K – United Cerebral Palsy (UCP) relationship was born.

UCP is a nationwide network of more than 110 community-based affiliates that provide services to families and caregivers of infants, children and adults with disabilities. The direct services provided by UCP affiliates range from medical treatment to employment and social programs. Every year more than one million people with cerebral palsy and other disabilities receive assistance from UCP affiliates in 39 states. Interestingly, more than 65 percent of the people served by UCP have a disability other than cerebral palsy. Through the years, UCP has become a leader in the disability field, and is consistently ranked as one of America's most financially responsible charities.



Circle K's relationship with UCP started at a simple backyard barbecue. Gradually, Circle K stores began collecting coin donations from customers, sending the donations to UCP. Today, the Circle K brand of convenience stores continues a tradition of support that began in 1984 when The Circle K Corporation purchased the Utotem chain of convenience stores. After the acquisition, Circle K management adopted UCP as the company's charity-of-choice. To date, the nationwide network of Circle K convenience stores has raised more than $36 million for UCP through coin canister collections and special events.

Lead Customer Service Representative Anna Hall asks customer if he would like to donate his extra change to the UCP canister collection program.

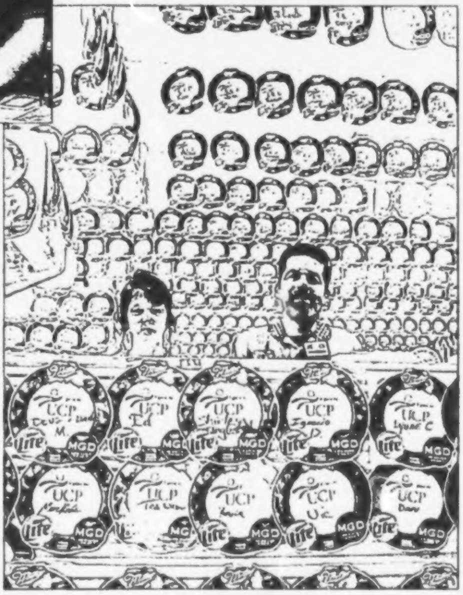
The most visible Circle K fundraising program is the annual holiday promotion in conjunction with Miller Brewing Company. Every November and December, Circle K customers are invited to make a one-dollar donation in exchange for recognition on a paper holiday wreath. Each personalized wreath is then displayed on Circle K walls throughout the holiday season. This successful program raised more than $500,000 in 2001.

But the Circle K store employees who meet the public on a daily basis are the heart and soul of this incredible philanthropic movement. They are committed to doing their share to support the independence of people with disabilities. As Lead Customer Service Representative Anna Hall says, "I have met children and their families that have been helped by UCP and my heart has been deeply touched . . . I truly believe in this [UCP canister collection] program."

Wanting to be part of something larger than oneself and finding a way to help others are uppermost in the minds of many Circle K employees. "Our employees have great heads for business, large hearts for people," says Mick Parker, manager of company operations for Circle K. "We're very proud of them." Circle K District Manager Ardie Killion confirms that appraisal in her description of outstanding UCP fundraiser Linda Reynolds, "Linda has been the number one collector of UCP funds in the company for the past five years. There is no other employee in the company that is as dedicated as this lady."

Another store manager, from Circle K's southern region (encompassing Louisiana, North Carolina, South Carolina, Georgia, Tennessee, Virginia and New Jersey), has this appraisal of employee Trudy Parmeter: "Trudy has been employed by Circle K for nine years, and devotes most of her time to UCP fundraisers and events. Not only does she work full-time and go to school full-time, but she is a mother of three children . . . for the past two years, she has promoted car washes and food drives to benefit UCP."

Circle K's Albuquerque, NM District Manager Tom White has this to say about Hazel Phillips: "Hazel is 75 and never lets up – she asks customers every day to donate to UCP. Hazel also has raised the performance of her fellow employees by her example."



During the annual holiday fundraiser, customers donate $1 to UCP to have their name placed on a paper decoration and hung within Circle K stores nationwide. Store #1966 sold an outstanding 2,998 paper decorations during the two-month promotion.

"Leadership by example is the key for this tight-knit company and its compassionate employees, who think of others first while serving the public in their communities," says UCP National Volunteer President E. Hal Nolan. So the next time you rush into a Circle K, in a hurry, to pick up that soda or loaf of bread, pause for a minute and look at the smiling face that asks you to share your change to make a difference in someone's life.

UCP Executive Director Kirsten A. Nyrop adds: "Citizen Circle K is a shining example of how corporations, employees and responsible charitable organizations can really make a difference in the lives of the people they serve while still upholding and accentuating the company's mission!" **EP**

Paul T. Burke is the director of marketing and communications for UCP.

THE SURGEON GENERAL FOCUSES THE NATION ON Health and Mental Retardation

Duane Alexander, MD
Director, National Institute of Child Health and Human Development

When Surgeon General David Satcher called for a national conference on health and mental retardation (MR), he made it clear that he wanted to bring together "experts, and especially parents...and persons with mental retardation...to talk about what we know and what we do not know." With this pledge at a March 2001 congressional hearing, he launched an extraordinary process that led to the publication, in February 2002, of the report of the first-ever Surgeon General's Conference on Health Disparities and MR.

The new report, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*, is based on the findings and recommendations of the December 2001 conference, held in Washington, DC. The report draws attention to the health and healthcare needs of people with MR. In recent years, public policies have tended to focus less on their health than on deinstitutionalization, community living, education and employment. Although more precise data are needed, there is convincing evidence that people with MR are less healthy and more likely to miss out on appropriate healthcare than others without this condition.

The report states six broad goals to enable children, adolescents and adults with MR to live healthier lives with the support of their families and communities. It offers specific action steps and potential strategies for moving toward the goals. It also presents thumbnail sketches of several promising programs that now provide general and specialized healthcare to people with MR living in the community. And the report suggests many potential partners, from families to local, state, and national agencies and organizations, that could work together on action steps and strategies.

> The report states six broad goals to enable children, adolescents and adults with MR to live healthier lives with the support of their families and communities.

According to Eunice Kennedy Shriver, longtime advocate for people with MR—she received the Surgeon General's Medallion from Dr. Satcher at the conference—the December meeting was the first to be devoted exclusively to the health of people with MR. As the meeting began, researcher Sharon Ramey said, "I've waited thirty years for today." After the conference, Kim Daniels, a parent consultant to the Vermont Self-Determination Project, wrote that as the conference progressed, she felt years of frustration and anger being replaced with hope.

The publications of the Surgeon General can be catalysts for action at every level of society. For example, since the first Surgeon General's report on smoking and health, in 1964, there have been sea changes in attitudes toward tobacco of policymakers, healthcare providers and the American public. As the smoking story suggests, progress on a health issue can be both widespread and sustained when initiated by a Surgeon General's report. "People respect these reports and act on them, especially when they deal with a topic as important as health disparities and MR," Dr. Satcher told the conference. He urged participants to start the process of change in their own communities. "Together, we must move these issues to the front of the American health agenda," he said.

Why pay special attention to health and MR? "MR" is one term for a cluster of specific disabilities that vary in intensity and that affect learning and

Material contained in this report is in the public domain and may be used and reprinted without special permission; appropriate citation to source should read: Reprinted from EP Magazine, 65 E. Rte 4, River Edge, NJ, 07661; (800) 372-7368; web site: http://www.eparent.com.

THE GOALS OF *CLOSING THE GAP: A NATIONAL BLUEPRINT*

TO IMPROVE THE HEALTH OF PERSONS WITH MENTAL RETARDATION

1. Integrate health promotion into the community environment of people with mental retardation. Action steps address educating and supporting individuals with MR and their families and direct support professionals (DSPs) in self-care and wellness, care burdens on families, turnover among DSPs and protection from occupational hazards for people with MR.

2. Increase knowledge and understanding of health and MR, ensuring that knowledge is made practical and easy to use. Action steps address participation of the community of people concerned with health and MR in identifying research priorities, a national research agenda, data collection, protection of research subjects, understanding and use of research findings, research capacity and visibility of health and MR research.

3. Improve the quality of healthcare for people with MR. Action steps address priority areas for healthcare quality improvement, standards of care, the role of practice, organization and financing of healthcare services in quality improvement and recognition of excellence in provision of healthcare to persons with MR.

4. Train healthcare providers in the care of adults and children with MR. Action steps address basic and specialized training of healthcare providers, continuing education for established providers, interdisciplinary education and training, and provider competencies.

5. Ensure that healthcare financing produces good health outcomes for adults and children with MR. Action steps address relationships among healthcare financing, service packages, outcomes and accountability, definitions of "effective" and related terms in research, the organization and financing of healthcare, access to appropriate packages of services, leveraging health dollars for maximum purchasing power, and offsetting specialized costs to healthcare providers in extra patient time and other factors

6. Increase sources of healthcare services for adults and children, ensuring that healthcare is easily accessible for them. Action steps address the numbers and diversity of trained and experienced healthcare providers, complexities in access to health services, community-based healthcare, allied health professionals, supportive services for providers (e.g., case management), specialized equipment at clinical sites and continuity of care across the lifespan.

acquisition of particularly complex adaptive skills. There is no single, generally-agreed-upon term for this type of disability, which is also called "intellectual disability," "cognitive disability," "developmental disability," and other specialized terms. For most people with MR, the condition is mild. With appropriate support they are able to live, go to school and work in their communities.

Like anyone else, people with MR need primary care and specialized health services that are family-centered, easily accessible, responsive to their cultural values, and appropriate for their medical condition, their age and their personal goals. Such care can be exceptionally difficult to find in most communities. As one conference participant said, "There are many benefits of deinstitutionalization, but having resources in the community has not been one of them."

In part, the difficulties of people with MR and their families are those that other vulnerable populations are also likely to encounter. For example, according to reports of parents and primary care providers and data presented at the conference, many doctors, dentists and other providers believe that Medicaid reimbursement rates are inadequate and program rules too complicated. For these reasons, they may restrict

continued on page 32

Laura and John Noble and sons Jeffrey and John participate in Operation HouseCall (see p. 30).

OPERATION HOUSECALL: BOSTON PARENTS TEACH MEDICAL STUDENTS ABOUT SPECIAL NEEDS CHILDREN AND THEIR FAMILIES

Stories about doctors and other practitioners – every parent of a child with special healthcare needs has them. There are doctors who talk directly to children – even those who do not answer verbally – and who easily share information and decision-making. But there are also doctors like the one who did not talk to Susan Nadworny about her infant son's seizures. "All of a sudden, twelve people trooped into the room, " she recalls. "And they said, 'This is your epilepsy team.' And that's how I found out his diagnosis."

To help future doctors better recognize family needs and strengths, Susan now coordinates specialized training for third-year students at Boston University School of Medicine (BUSM). The training, "Operation HouseCall," sends students for extended visits to homes of children with special healthcare needs and their families.

Before their visits, students are often apprehensive and concerned that they will be intruding upon families. Susan assures them that families are eager to introduce the students to their children, and to help them understand that children must be treated as part of the family unit. After the visit, says Susan, the students' "fears are allayed and they really appreciate the visit." According to a study published in 1998, the training is associated with measurable, positive changes in students' attitudes toward children with disabilities and their families. Students overwhelmingly said that they found the training useful.

Participants in the Surgeon General's Conference on Health Disparities and Mental Retardation, held in December 2001, heard about the program from Boston neurologist Dr. David L. Coulter. The program began about ten years ago, after the Greater Boston Arc (GBArc) approached the medical school about improving physicians' attitudes toward people with mental retardation. Dr. Coulter worked with GBArc in developing Operation HouseCall, now overseen by Dr. Benjamin Siegel, director of medical school education and pediatrics at BUSM. "This started with the parents, not us," Dr. Siegel says. From the start, parents have designed the curriculum and taught the students.

Volunteer families. Sixty families of children with special needs currently volunteer to invite medical students into their homes for visits lasting about four hours. Their children range in age from preschool to young adults. Often, but not always, their disabilities are cognitive. Susan coaches the families about the medical student visits. She tells them that the students are not visiting to provide care to their children. Instead, "They're here to ask questions. They're here for you to teach. Think about the message you want them to leave with."

Classroom education. Every six weeks, as each pediatrics rotation begins, Susan meets with the students on the rotation for a two-and-a-half-hour orientation. She begins by asking about their knowledge and attitudes about disability. She asks them to think about how they would prefer to be told if they had a child with a disabling condition. She illustrates her talk with her own experiences. When she first saw her newborn son, she recognized that he had Down syndrome, but her physician said only that they had suspicions.

Susan's talk takes students through the lifespan of a person with disabilities, from infancy and early intervention to school, adolescence, the transition to adulthood and concerns of aging parents about their adult children. She discusses legal rights, special education and community resources. She shows videos: one takes students into an inclusive school classroom; another describes needs of elders and families.

Students receive a packet of handouts, the first a welcoming letter from Susan. The packet includes a short list of questions that students could ask to get conversations going with parents. Other handouts list web sites where students can learn quickly about the condition of the child they will visit, and translate common acronyms, such as "IEP," into English – "Individualized Education Plan." One handout is a candid list of "dos" and "don'ts" for students to remember when they visit with families. They are advised, for example: "Do say, 'I'm sure you will do what's best.' Do say, 'I don't know,' when you don't."

Home visits. Host families structure the home visit, which often occurs at dinner time but may be a trip to a park or an evening talk with pizza. The primary goal of the visit is to help students understand how a child's disability affects a family— "and to see how the child is a member of the family, and needs to be respected," Susan says.

Student evaluations. At the outset of the training, students fill out profiles that indicate their knowledge and attitudes about disabilities; after the visit, they write about their experiences.

According to Drs. Siegel and Coulter, Operation HouseCall is a low-cost, effective way to shape student attitudes while their "medical personalities" are still being formed. Demands on student time are minimal and Susan's work is supported by a small grant. They have several suggestions for parents who would like to start similar training programs in their local medical schools. First, it is important to have a faculty champion within the school. Second, the school must "legitimize parents as faculty." For example, the Boston medical students are advised that they must complete scheduling their home visits in the first two weeks of their pediatrics rotations. The penalty for missing the deadline is an automatic low grade on a student's academic record. A third strategy would be to frame the program as a way of teaching students about working effectively with patients, whether or not they have disabilities.

The curriculum for the Operation HouseCall training, including the information packets provided to the medical students and a video prepared for medical school faculty, are all available from Greater Boston Arc. Anthony Sirignagno, Director of Advocacy and Community Services at GBArc, says that more than 100 medical schools have contacted him about the training, and that it is currently being used at about a dozen schools. To request the curriculum materials and the video, contact Greater Boston Arc, 617-783-3900, gbarc1@msn.com, or www.gbarc.org.

Independence means different things to different people. For children with bladder or bowel control problems, it could just mean getting through the day dry. That's why something as simple as a change in clothing, can, even in a small way, change a child's way of life.

WHY CHILDREN WHO RELY ON GOODNITES ARE MORE INDEPENDENT.

GoodNites® absorbent underpants can help a child become more independent. With GoodNites, accidents won't become catastrophes. So your child will be able to do more. Plus, because they look like real underwear, kids don't mind wearing them. And since they're easy to pull on and off, they can make a child feel more self-reliant.

GoodNites are available in 3 sizes: 45–65 lbs., 65–85 lbs., and 85–125 lbs. That means finding the size that fits your child will no longer be a problem. Plus they have tear-away sides and they're latex-free.

- *Day and nighttime protection*
- *Latex-free*
- *Tear-away sides for easy removal*
- *Three sizes, to fit kids from 45–125 lbs.*

Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS
45 lb & over

For Better Days.

Imagine your child gaining a little more independence just by a change in clothing. For information on how GoodNites can help, and a free sample offer, please visit us at www.goodnites.com/offer

BEST COPY AVAILABLE

®Registered trademark of Kimberly-Clark Corporation. ©2000 KCC.

Circle #54 or visit www.eparent.com/adinfo

Dr. Satcher addresses conference participants.

Daniel Rej and his father Henry Rej are Operation HouseCall volunteers.

Duane Alexander, MD, Director, National Institute of Child Health and Human Development, addressing the Conference on Health Disparities and MR.

continued from page 29

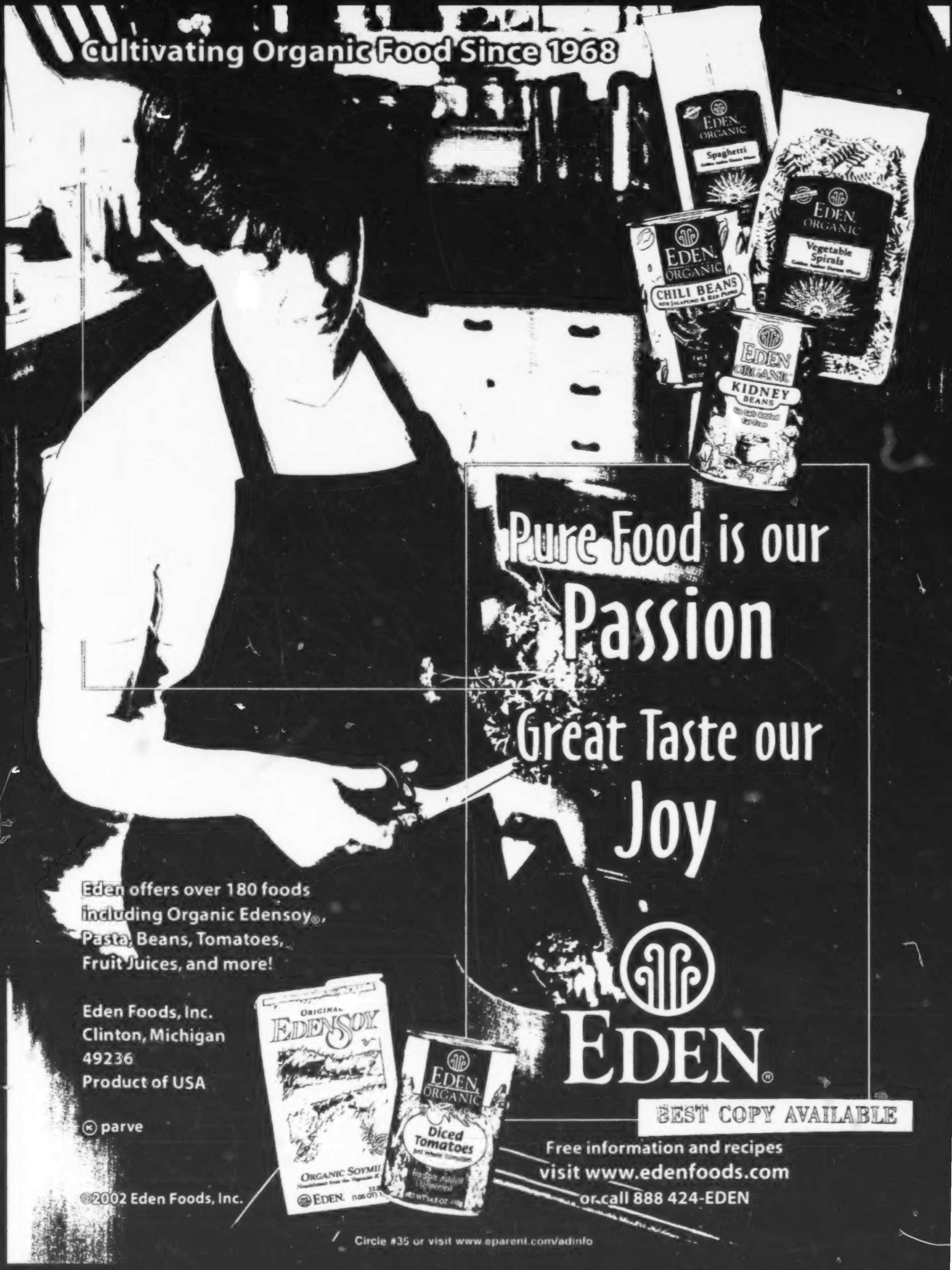
the number of Medicaid recipients in their practices, or refuse to accept these patients at all, regardless of disability or medical condition. Such restrictions make the providers inaccessible to the estimated 60 percent of people with MR who rely on Medicaid as their only source of healthcare coverage.

And for people with MR, there are additional challenges in staying healthy and getting satisfactory care. Healthcare providers rarely receive the type of training that would enable them to feel competent in treating and interacting with people with MR. Dr. Kathleen Braden, a Massachusetts-based developmental pediatrician, identified a number of promising programs—summarized in *Closing the Gap*—that accommodate the special needs of people with MR. Dr. Braden says it takes special skills to distinguish among cognitive disability, symptoms of depression and, for example, attitudes and behaviors that are common in adolescence. "Some providers still cannot see beyond the disability to the person," notes Dr. Braden. According to some providers, community mental health centers may exclude people with MR. Such exclusions may reflect mistaken beliefs that children, adolescents and adults who are cognitively challenged cannot benefit from psychotherapy and counseling.

Susan Nadwomy coordinates Operation HouseCall and is the principal trainer. Their experience when son James (r) was born prompted Susan and husband John (c) to become involved with the program.

As the programs summarized in *Closing the Gap* suggest, good results can be expected when healthcare is attuned to the cognitive abilities of people with MR. This is particularly true of programs built on principles of individual autonomy and self-determination. One conference participant urged better dissemination of information about existing, community-based health services. "There are many

continued on page 34



Cultivating Organic Food Since 1968

Pure Food is our Passion

Great Taste our Joy

EDEN®

Eden offers over 180 foods including Organic Edensoy®, Pasta, Beans, Tomatoes, Fruit Juices, and more!

Eden Foods, Inc.
Clinton, Michigan
49236
Product of USA

Ⓚ parve

©2002 Eden Foods, Inc.

Free information and recipes
visit www.edenfoods.com
or call 888 424-EDEN

EDEN ORGANIC
Spaghetti
EDEN ORGANIC
Vegetable Spirals
EDEN ORGANIC
CHILI BEANS
EDEN ORGANIC
KIDNEY BEANS
No Salt Added
ORIGINAL EDENSOY
ORGANIC SOYMILK
EDEN
EDEN ORGANIC
Diced Tomatoes

BEST COPY AVAILABLE

Circle #35 or visit www.eparent.com/adinfo

Elizabeth Kipstein (l) and mom Patricia Kipstein (r) help train third-year medical students to recognize family needs and strengths through Operation HouseCall.

continued from page 32

good programs out there. Let's take the best of our good ideas and not start at square one when we try to help people."

There also is published evidence that with appropriate training, especially before they enter practice, health professionals can learn to see and value the person, rather than just the disabling condition. "Our people coming out of medical school are our best hope," according to Boston neurologist David L. Coulter, MD.

How was the *Closing the Gap* report developed? In planning the conference, the Surgeon General asked the public to submit comments to a special web site; he also listened to comments at the nationally videocast listening session in October 2001. The result was hundreds of written and verbal comments from self-advocates with MR and their families, primary and specialized healthcare providers, researchers, program administrators and others concerned with health and MR. These comments helped to identify eight major issues for the conference to address, ranging from provider attitudes toward people with MR to the quality and financing of their healthcare, their access to services, and their role in staying healthy. (The listening session is summarized in *Closing the Gap.*)

The conference began on December 5 with presentations of existing data and research needs for each of the eight issues. These were coupled with descriptions of health programs that address some of the issues. Then the 160 conference participants met in small work groups to identify high-priority issues, develop action steps, discuss research and resource needs and identify potential partners to help in implementing ideas. Joseph M. Valenzano, Jr., President, CEO & Publisher of EP and Rick Rader, MD, Editor-in-Chief, were among the invited participants.

Enjoy the out-of-doors together with a
CycleTote® Bicycle Trailer
Running Stroller
1-800-747-2407 www.cycletote.com
Satisfaction Guarantee/Lifetime Warranty

Work group membership mirrored the diversity of the conference as a whole. According to one moderator, members of her group "ranged from the executive director of the Daniels household to the parent of a child with ADHD, a member of the Sioux tribe, the deputy director of the Arc and a Social Security wonk. and all of these folks came together in diversity, to unite around certain core values." On the second day of the conference, moderators presented highlights of their group's chosen issues and recommendations; additional suggestions emerged in discussions at the full conference.

In drafting the report, the biggest challenge was finding the best way to capture the hundreds of ideas and suggestions that bubbled up in conference sessions and work group discussions. "We had 28 issues. We could have had more," said one group moderator. In scale, ideas and action steps ranged from realigning Medicaid, to make it more responsive to outcomes of importance to people with MR and their families, to surveying a single doctor's practice, to asking families of children with special healthcare needs about arrangements that would make office visits easier. In one work group, a parent suggested a way to solve a research problem that had challenged academic investigators. In describing her group's discussions, psychiatrist Roxanne Dryden-Edwards told the conference, "I can't say how much I've learned" from parents and self-advocates. "They may need us, occasionally, but we professionals need them."

What can exceptional parents do? The goals, action steps and potential strategies of the new report are ambitious and wide-ranging. Research agendas are called for. Better financing of healthcare services is recommended. Community support to protect the

continued on page 38

One of a kind

There are no formulas at Heartspring, just ongoing dedication to helping children with multiple disabilities achieve their fullest potential. Our multi-disciplinary approach recognizes each child as an individual and provides a plan customized for their specific needs. Your child is one of a kind. Why should their education be anything less?

Heartspring
School

Finding New Ways for Learning

8700 East 29th Street North • Wichita, Kansas 67226
www.heartspring.org

1-800-835-1043

Families in New Jersey and Connecticut:

A Heartspring representative will be in New Jersey **May 9-11** and in Connecticut **May 10** to discuss an educational setting unlike any other for your exceptional child. Call today to arrange your appointment.

Circle #20 or visit www.eparent.com/adinfo

ADVERTISEMENT

Universal Newborn Screening

In 1961, Dr. Robert Guthrie of the University of Buffalo developed a laboratory test to detect phenylketonuria (PKU) in newborns. PKU is an inherited metabolic disorder resulting from an enzyme deficiency; if left untreated, it results in profound mental retardation. In 1963 Massachusetts became the first state to mandate screening for PKU, which can be treated by lifelong dietary management and counseling. The National Association for Retarded Children (now The ARC), the Children's Bureau and the Kennedy Foundation were foremost among the organizations that pushed for widespread adoption of the Guthrie test, and by 1966 it was required for all children by all 50 states and the District of Columbia.

Dr. Guthrie and other researchers continued to develop newborn screening (NBS) tests to detect many more disorders, and each state decided what screens would be available for its newborns. Significant disparities resulted; in 1997, in Massachusetts, infants were tested for 10 or more disorders, while Utah's babies were screened for three. Montana and South Dakota each mandated three tests and offered one other by special request only. In the same period, with the introduction of ever-smaller and more powerful microprocessors, technology and equipment became significantly more sophisticated. This permitted testing that had not been feasible before. A process called tandem mass spectrometry (tandem MS, MS/MS) can now run tests for nearly 40 disorders at one time. None are curable, but all are treatable.

In the last two years, many states have expanded their NBS programs. Almost all Pennsylvania hospitals now offer the full spectrum of testing, although the law mandates testing for only six. Massachusetts routinely screens for more than 15 disorders and is running a pilot program offering 30+ tests. Wisconsin has almost tripled availability, from 7 tests to 20. Yet universal NBS still engenders much controversy, and there are many issues to be resolved before consensus can be reached on how the US will move forward.

ISSUES: These may be economic, political, professional, sociocultural, religious. Capital spending, training, payment policies, long-term follow-up; insufficient hard financial data; union issues; professional knowledge levels and practice habits; citizen knowledge, and cultural and religious beliefs and practices; insurance, managed care companies, Medicaid, ChIP programs, the uninsured—all these and many more must be part of discussions and resolution.

With the current system, a child born in Louisiana with galactosemia will likely live a life marked by mental retardation and other special health care needs, while similarly affected children born the same day in most of the rest of the country will receive immediate treatment and become productive members of society. The data tell us that of the four million babies born in the US each year, ten to twelve thousand will have one or more of these detectable disorders, an almost-negligible number. The overall cost or benefit to our society, though, will vary wildly from one child to another because of the patchwork of screening availability. We as a nation must find a way to embrace universal NBS and make it routine for all children born in the US. More than that, it is downright wrong not to do so when it has proven its worth time and again!

It is a question of education and awareness. Research shows that the average couple planning to have children does not know anything about existing screening programs, much less the capabilities offered by tandem MS, largely because OB/GYNs, pediatricians, genetic counselors and related professionals are not familiar with universal NBS. The education gap relates to professionals and consumers, rich and poor, people of every race, religion and ethnicity. Few people know much about any of the issues. Worse, among the people who do profess knowledge of NBS and the issues, a good deal of what they "know" is wrong.

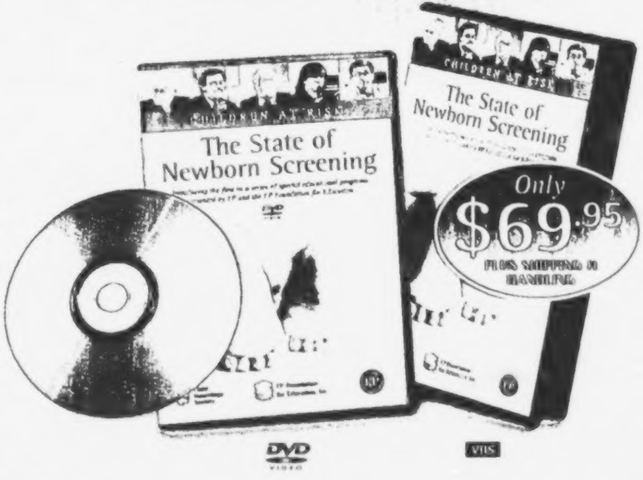
The data tells us that of the four million babies born in the US each year, ten to twelve thousand may have one or more of these detectable...and treatable...disorders

The information you need on Newborn Screening is finally available on DVD and video

Children at Risk:

The State of Newborn Screening

is now available on DVD and VHS. Introducing the first in a series of special educational programs presented by EP and the EP Foundation for Education, Inc., a 501(C)3 Not For Profit Corporation.



EP Foundation for Education, Inc. **Child Neurology Society** EP

Newborn screening can detect up to 39 metabolic disorders from one blood spot. All are treatable when diagnosed at birth, offering the chance for a full and productive life.

Leading medical and scientific professionals are gathered to provide the most current information available. You can view this valuable resource at your convenience and the DVD is indexed so that key topics are easily accessible.

Darryl DeVivo, MD
SIDNEY CARTER PROFESSOR OF NEUROLOGY
COLUMBIA UNIVERSITY

Piero Rinaldo, MD, Ph.D.
DIRECTOR, BIOCHEMICAL GENETICS LABORATORY
MAYO CLINIC

Edwin Naylor, Ph.D.
PRESIDENT
NEOGEN SCREENING, INC.

Joan E. Pellegrino, MD
ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES
UMDNJ, ROBERT WOOD JOHNSON MEDICAL SCHOOL

Paul M. Fernhoff, MD
MEDICAL DIRECTOR
EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #49 or visit www.eparent.com/adinfo

Duane Alexander, MD, Director, NICHD (2d l) and Surgeon General Satcher (2d r) flanked by colleagues.

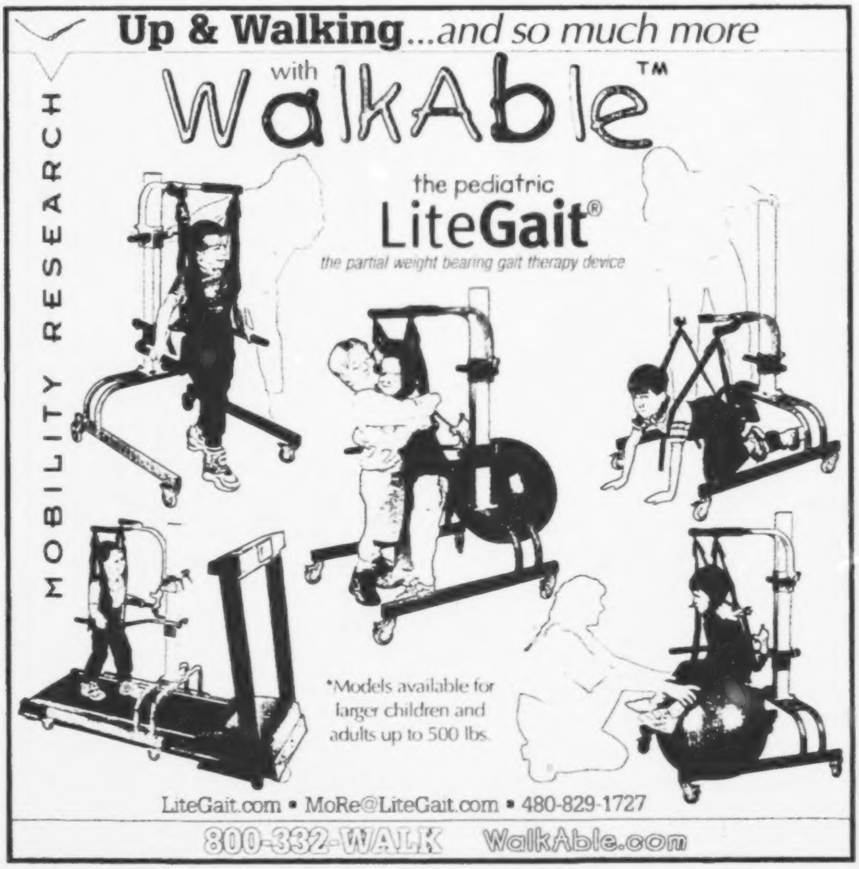
A self-advocate attending the Surgeon General's Conference.

continued from page 35

health of people with MR is suggested. Individualized health planning across the lifespan of an individual with MR is urged. And core values, applicable to all report recommendations, are framed in quotations from conference participants. Perhaps the most pervasive value, as expressed by one participant, is that there must be "coordinated, community-based services that are integrated, available and accessible. Let's not make it all so difficult."

Threaded throughout the report are the insights and ideas of the family members and self-advocates who joined with professionals in the work group decisions and floor discussions of the full conference. Dr. Dryden-Edwards described the experience of one mother in her group, whose 6-year-old child had participated "in as many research protocols as he is old." The group agreed that the impact of these experiences on the child and family should be part of the design of research projects.

In several groups, parents and physicians, nurses, physician assistants and other clinicians described their needs for easy access to scientific literature in lay language, which addressed areas of concern to them. In *Closing the Gap*, these experiences translate into a goal, not only to "increase knowledge and understanding of health and MR," but also to "ensure...that knowledge is made practical and easy to use." Among the action steps and potential strategies of this goal are enabling family members to



Up & Walking...and so much more
with WalkAble™
MOBILITY RESEARCH
the pediatric LiteGait®
the partial weight bearing gait therapy device
*Models available for larger children and adults up to 500 lbs.
LiteGait.com • MoRe@LiteGait.com • 480-829-1727
800-332-WALK WalkAble.com

Circle #61 or visit www.eparent.com/adinfo

Participants discuss issues raised in conference workshops.

involved in research by including them in advisory committees and helping them understand how to frame research questions and other technical issues.

At the end of the conference, Dr. Satcher charged participants to use the forthcoming report on the conference recommendations as a resource. Self-advocate and Special Olympics athlete Loretta Claiborne concluded that "The consensus of this conference is to take action–and I really mean action." EP

The report *Closing the Gap* may be downloaded from: *http://www.surgeongeneral.gov/library/conferences.htm*. Choose *Closing the Gap*. Or *http://www.nichd.nih.gov/publications/pubs/closingthegap/index.htm*.

For single copies of the report, contact:

The NICHD Information
Resource Center
P. O. Box 3005
Rockville, MD 20847
Phone: (800) 370-2943
Fax: (301) 984-1473
Web site:
http://www.nichd.nih.gov/publications
E-mail:
NICHDClearinghouse@mail.nih.gov

With the Creepster Crawler, You Can Watch Your Child Crawl for the First Time!

Children lacking head control, the ability to roll over or belly crawl have gained mobility with the ***Creepster Crawler.*** Using this light, innovative device, hundreds of children around the world are crawling, working more productively with their therapists, and gaining a head start to more advanced mobility in the future.

The ***Creepster Crawler*** is an ideal solution for youngsters with debilitating conditions such as ☐ Spina Bifida ☐ Down Syndrome ☐ Cerebral Palsy ☐ TBI, and ☐ developmental delays. Children with tracheostomies and G-Tubes also are successful users of the ***Creepster Crawler***.

The ***Creepster Crawler***'s frame has a padded platform that can support a parent or therapist from above, making it easier to work with the child on weight-bearing, weight-shifting, reaching and creeping. Front shoulder, chest and rear straps can be adjusted for individual fit.

Please visit our Worldwide Web site at www.redbarn-enter.com for additional details and a video demonstration of the ***Creepster Crawler***.

Call for a Brochure!
1-800-577-1317
Fax:1-602-242-9211
or email us at info@red-enter.com

RedBarn
ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.redbarn-enter.com**

CAUTION: Children should not be left unattended in the Creepster Crawler.

Circle #66 or visit www.eparent.com/adinfo

Get a FREE bladder control products catalog from the caring professionals at HDIS.

HDIS

Convenient Home Delivery of Bladder Control Products

At HDIS, we've been providing discreet home delivery of bladder control products for more than 16 years.

Our friendly, knowledgeable Customer Care Representatives will help you choose which products are right for your child, and answer any of your questions.

Name brands always in stock—Depend®, Attends®, Reassure®, Tranquility® and more!

FREE CATALOG!
Call 1-800-2MY-HOME®
(1-800-269-4663)

"If you have any questions, give us a call. We'd be happy to help."
– Mary

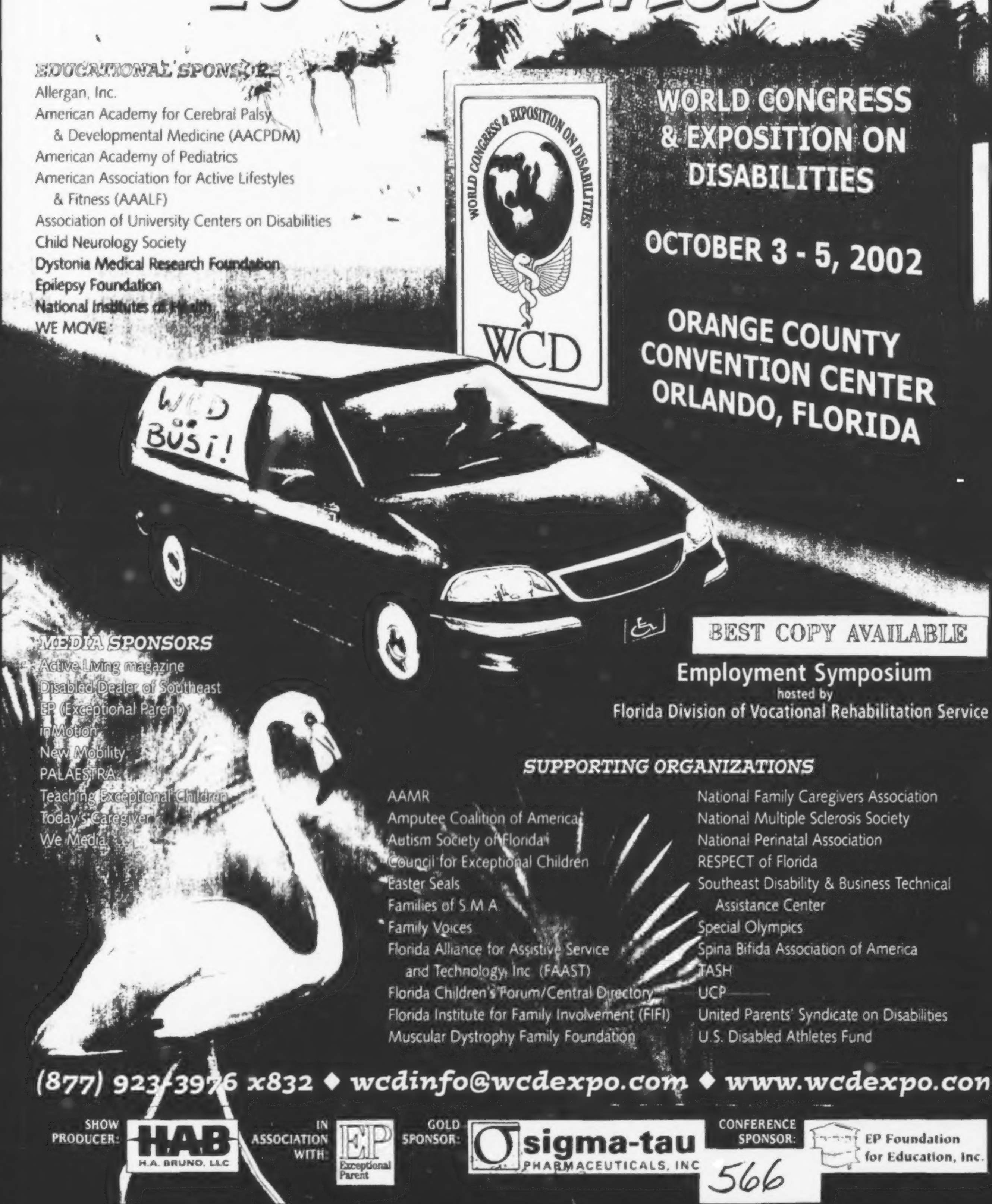
Call now to get your FREE 40-page HDIS catalog of bladder control products and over $45 in coupons—all sent to you in a discreet envelope.

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

024-129

Circle #44 or visit www.eparent.com/adinfo

On The Road To Orlando



EDUCATIONAL SPONSORS

Allergan, Inc.
American Academy for Cerebral Palsy
  & Developmental Medicine (AACPDM)
American Academy of Pediatrics
American Association for Active Lifestyles
  & Fitness (AAALF)
Association of University Centers on Disabilities
Child Neurology Society
Dystonia Medical Research Foundation
Epilepsy Foundation
National Institutes of Health
WE MOVE

WORLD CONGRESS & EXPOSITION ON DISABILITIES

OCTOBER 3 - 5, 2002

ORANGE COUNTY CONVENTION CENTER ORLANDO, FLORIDA

BEST COPY AVAILABLE

MEDIA SPONSORS

Active Living magazine
Disabled Dealer of Southeast
EP (Exceptional Parent)
InMotion
New Mobility
PALAESTRA
Teaching Exceptional Children
Today's Caregiver
We Media

Employment Symposium
hosted by
Florida Division of Vocational Rehabilitation Service

SUPPORTING ORGANIZATIONS

AAMR
Amputee Coalition of America
Autism Society of Florida
Council for Exceptional Children
Easter Seals
Families of S.M.A.
Family Voices
Florida Alliance for Assistive Service
  and Technology, Inc (FAAST)
Florida Children's Forum/Central Directory
Florida Institute for Family Involvement (FIFI)
Muscular Dystrophy Family Foundation
National Family Caregivers Association
National Multiple Sclerosis Society
National Perinatal Association
RESPECT of Florida
Southeast Disability & Business Technical
  Assistance Center
Special Olympics
Spina Bifida Association of America
TASH
UCP
United Parents' Syndicate on Disabilities
U.S. Disabled Athletes Fund

(877) 923-3976 x832 ◆ wcdinfo@wcdexpo.com ◆ www.wcdexpo.con

SHOW PRODUCER: HAB H.A. BRUNO, LLC
IN ASSOCIATION WITH: EP Exceptional Parent
GOLD SPONSOR: sigma-tau PHARMACEUTICALS, INC
CONFERENCE SPONSOR: EP Foundation for Education, Inc.

566

Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—October 3 - 5, 2002
LOCATION:
Orange County Convention Center—Orlando, Florida

A UNIQUE GATHERING—A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract **physicians** ◦ **families** ◦ **direct support professionals** ◦ **people with disabilities** ◦ **allied health care professionals** ◦ **educators** ◦ **adapted physical education specialists.**

TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.

SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more.

EMPLOYMENT SYMPOSIUM PAVILION: Human resource managers will discuss career opportunities.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.

CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment. (See next page for complete program).

- CME and CEU accreditation will be provided through approved accreditation institutions.
- An Employment Symposium produced in conjunction with the Florida Department of Education, Division of Vocational Rehabilitation Services will offer sessions for people with disabilities, their families and employers.

WCD

Please send me information on the World Congress & Exposition on Disabilities, October 3-5, 2002

I AM INTERESTED IN: ☐ Exhibiting at the Show ☐ Attending the Show

Name

Company

Address

City State Zip Code

Telephone Fax

Email

Send Me Information:
877-923-3976, x832
Fax this page to:
201-226-1236
Mail this page back to:
WCD
210 Route 4 East
Suite 403
Paramus, NJ 07652
Email your request from:
www.wcdexpo.com

EP5/02

October 3-5, 2002 • WORLD CONGRESS & EXPOSITION ON DISABILITIES

SOMETHING FOR EVERYONE: THE WCD CONFERENCE PROGRAM

The third annual World Congress & Exposition on Disabilities (WCD), produced by H.A. Bruno, LLC, will feature over 150 multi-disciplinary educational sessions developed by the EP Foundation for Education, Inc., a 501(C) 3 not-for profit organization, with the assistance of EP Exceptional Parent Magazine and supported by the Academy of Pediatrics, the National Institutes of Health, the Child Neurology Society, The Association of University Centers on Disabilities (AUCD), WE MOVE and other professional societies and organizations. An extensive adapted physical activity program, sponsored by PALAESTRA Magazine, will again be offered. Each session is designed to educate many disciplines within the disability community. During the intensive three-day educational experience, information and ideas on today's most important issues will be exchanged between people with disabilities, their families and caregivers, physicians, direct support professionals, allied health care professionals, educators and adapted physical education specialists. The conference will take place October 3-5 at the Orange County Convention Center in Orlando, Florida.

"That event (the World Congress & Exposition on Disabilities) was magnificent. You have a subgroup, a session, for every subject under the sun. It's the most comprehensive educational program I've ever seen in any one setting," stated Florida Governor Jeb Bush, a scheduled Guest Speaker this year in Orlando. In addition, the WCD conference program is collaborating on a 50 session employment symposium with the Florida Department of Education, Division of Vocational Rehabilitation Services (VRS) and other statewide provider/advocacy organizations, sponsored by VRS and McDonald's Corp. See upcoming issues for updates on employment symposium titles.

The 2002 session topics to date include:

WEDNESDAY, OCTOBER 2

- Physical Fun for Everyone
- The Top Down Planning Model
- The Circle of Rings-Collaboration between Teachers, Therapists and Families

THURSDAY, OCTOBER 3

- Oral Motor Patterns, Impairments and Therapy
- Pain and Pain Management Part I
- Management of Spasticity Arising Out of Central Nervous System Disorders
- The Role of the Pediatrician in Managing Great Care for a Child with Challenges
- A Web-Based Tutorial on Developing an Individualized Education Program
- Sense the Water: Understanding Sensory Integration and Skill Acquisition in Adapted Aquatics
- Therapeutic Recreation and Functional Ability of Older Adults
- Music and the Active Learner
- Adaptive Golf
- Geriatrics and the MR/DD Population
- Autism: What the Research Tells Us
- Pain and Pain Management Part II
- Teaching Empathy to MD Residents
- The Management of Dystonia and Other Movement Disorders Part I
- Seizures & Seizure Management: Brain Mapping & Surgical Intervention
- Working with Your Doctor - Keep Them on Their Toes!
- Utilizing Task Variation to Teach Motor Skills to Individuals with Autism or Developmental Disabilities
- Inclusion Strategies for Aquatic Programs
- Fall Risk Reduction: A Multidimensional Approach
- Relaxation for Students with Special Needs
- Are You Getting or Offering "State-of-the-Art" Behavioral Supports?
- More on Project DOCC Part I
- Caregivers: Caring for Others and Yourself
- The Management of Dystonia and Other Movement Disorders Part II
- Seizures & Seizure Management: Confirming Diagnosis and Assessing Treatment
- Louisiana GUMBO
- Designing and Implementing a Fitness Facility for The Physically Disabled
- Activities to Facilitate Inclusion of Exceptional Learners
- Carefully Designed Movement Activities to Facilitate Central Nervous System Development in Young Children with and without Disabilities
- When Information Is Not Enough: Using the Internet
- More on Project DOCC Part II
- A Communicative Approach Used for Autism, PDD and Aspergers
- The Management of Dystonia and Other Movement Disorders Part III
- Seizures and Seizure Management: From Febrile Seizures to Breakthrough Seizures
- In a Child's Room
- Augmentative and Alternative Communication Evidence-Based Clinical Practice Using Performance Measurement Tools
- Positive Behavioral Support in the Gymnasium: An Alternative to Behavior Management
- Radical Changes in the National Wheelchair Basketball Association's Youth Division
- Collaboration Between the Physical Therapist and the Physical Educator
- Activities to Facilitate Music and the Active Learner
- Attention Deficit Hyperactive Disorder (ADHD): Medication, Side Effects, and Physical Activity

FRIDAY, OCTOBER 4

- Transitioning: Advanced Education (Post Secondary)
- Appropriate Education for the Child with Autism: Courting the Schools and Avoiding Court
- PreVerbal and Early Verbal
- Learning Disorders and ADD/ADHD
- Universal Newborn Screening: Early Hearing Detection and Intervention
- A Parent's Story About Dealing with Mitochondrial Myopathy
- On The Road Again or For the First Time
- Adapted Physical Education in Korea
- Wake Up and Face the Facts! Parents as an Influence on Children's Physical Activity Levels
- Life-Long Involvement in Sports and Recreation for Deaf and Hard of Hearing Individuals
- Resistance Training for Individuals with Developmental Disabilities
- Challenging the Senses for Increased Balance and Postural Control in Older Adults: It's as Easy as 1, 2, 3
- Preschool Activities for Children with Disabilities
- An Adapted Aquatics Curriculum and Assessment Inventory
- Genetic Disorders and Counseling
- Language — Developing Conversational Skills in Children with Disabilities
- Universal Newborn Screening: What Is It and Why Is It So Important?
- Seizures and Seizure Management: The Ketogenic Diet
- What to Know about Clinical Trials for Rare Diseases
- A Review of Driving Technology Today
- Sport for Individuals with Mental Retardation in Eastern Europe and Eurasia
- Sign Language for Adapted Physical Activity Professionals
- Developing Rubrics for the Adapted Physical Educational Standards
- What Parents Can Do to Help Their Children Become Physically Fit
- Activities for Restricted Space
- Ai Chi Basic Class-Balance, Harmony and Healing
- Cognitive Skills and Aquatics
- Teaching Literacy (Whole Language & Phonics) to Adults with MR/DD
- Universal Newborn Screening: Detection, Screening and Treatment
- Lower Limb Prostheses 2002: Current State-Of-The-Art
- Creative Games and Activities that Use Low Cost or Free Equipment
- The Art and Science of Transfers: A Grand Collaboration
- Seizures and Seizure Management: The Vagus Nerve Stimulator
- The Spectrum of Mitochondrial and Metabolic Disorders
- Physical Fitness Programming for Individuals with Multiple Sclerosis
- Diabetes Exercise and Education Program Management
- Ai Chi Program for Children with ADD and other Neurological Impairments
- The National Alliance of Direct Support Professionals (NADSP)
- The Spectrum of Rare Disorders
- Dolphins and the Disabled
- Universal Newborn Screening: Screening Methodologies
- Women, Pregnancy and Epilepsy
- Perioxosomal, Lysosomal and Mitochondrial Disorders
- Legislation, Conformity, And Outcomes For People With Disabilities
- Inclusive Outdoor Education Programs for Students with Special Needs Part I
- Adaptive Snow Skiing
- Developmentally Appropriate Pedagogy for All Ages
- Practical Props for Special Pops
- Challenging the Senses: An Awareness of Sensory Distortions
- A Student Driven Adapted Aquatics Program

SATURDAY, OCTOBER 5

- IDEA Overview
- Realizing the Power of Choice: So Many Choices, One Goal
- Fun with Educational Math for People with Cognitive Disabilities
- Universal Newborn Screening: Why Screening is Important to Our Nation
- Overview of Veteran's and Survivors' Benefits
- Dealing with Managed Care Systems: Some Practical Perspectives on Reimbursement Issues
- Indispensable Tips, Tricks and Tools for Writing
- Darwin Was Right—You have to Adapt to Survive
- Adapted Aquatics Equipment, Programs, and Credentials for People with Disabilities
- Using Computer-Based Virtual Environments to Enchance Community Integration
- Coaching Athletes with Mental Disabilities
- Rhythmical Movement Vocabulary
- Latest Changes in IDEA: How Do They Effect Your Child
- Knowing Your Legal Rights
- Fun with Educational Math for People with Cognitive Disabilities Part II
- The Most Disability-Friendly Community in the US
- The Commercialization of Universal Newborn Screening (UNBS) Part I
- The Exceptional Family Member Program
- Ticket to Work Program
- Assistive Technology and Augmentative Communication
- Life-Long Involvement in Sports and Recreation for Deaf and Hard of Hearing Individuals
- A Cyberspace Class For Community College Adapted Physical Education: Stages of Collaboration
- Aquatics for Learners with the Pervasive Developmental Delay Spectrum: Autism, Asperger's Syndrome, PDD-NOS, and Rett's Syndrome
- Activities to Promote Inclusive Outdoor Education Programs Part II
- Adapted Martial Arts Program for those with Physical and Mental Disabilities
- Discipline and How It Affects your Child
- Estate Planning For Families Caring for People with Disabilities
- Transition From Hospital to Home: Supports and Services for Infants with Special Needs and Their Families
- Autism Spectrum Disorders: Myths and Realities
- The Commercialization of Universal Newborn Screening (UNBS) Part II
- How to Compose an Effective Individualized Education Program (IEP)
- Special Needs Trust (Community Trusts)
- Transition From Hospital to Home: Cultural Considerations
- Autism Spectrum Disorders: What We Know and What the Future Holds
- Universal Newborn Screening: The Role of Genetic Counseling
- Oral Healthcare for People with Disabilities and Special Needs Part II
- Personal Perspectives on Disabilities
- Prevention and Treatment of Skin Injuries Common to those with Amputations Participating in Adapted Physical Activity
- SCUBA Diving For People With Disabilities
- Carefully Designed Movement Activities to Facilitate Central Nervous System Development in Young Children with and without Disabilities
- Modifying and Teaching Tai Chi for Seniors and Individuals with Disabilities
- Inclusion in Team Sports: Modifications that Work for Everyone

EXHIBITORS

AAMR
Accessibility Services, Inc.
A.C.F. Environmental
Acorn Stairlifts Inc.
Active Living Magazine
Advanced Respiratory
Advantage Vans of Central Florida
Allergan, Inc.
American Academy for Cerebral Palsy & Developmental Medicine (AACPDM)
American Association for Active Lifestyles & Fitness (AAALF)
Amputee Coalition of America
Anew International
Angelman Syndrome Foundation
Anne Carlsen Center for Children
Aquatic Access Inc.
Aurora Ministries
Autism Society of Florida
Best Bath Systems
Beyond Adversity TV
Bodypoint Designs Inc.
Body Sense
Cambrooke Foods
Canine Companions for Independence
Challenge Publications
Child Neurology Society
Cloister Creek
Communication Access Network
Communicating Partners Center
Concord
Continental Press/ Seeding Publication
Convaid Inc.
Council for Exceptional Children
Crotched Mountain
David Mandt & Associates
DBH Attachments Inc.
Defense Threat Reduction Agency
Department of Veterans Affairs
Department of Defense Dependents Schools
Dietary Specialties
Disabled Dealer Magazine
Dolphin Human Therapy
Downi Creations, Inc.
Driving Aids Development Corp.
Dystonia Medical Research Foundation
Easter Seals
Economic Mobility
El Dorado
Emergency Caller Systems/Peat
EP (Exceptional Parent)
EP Foundation for Education, Inc.
Epilepsy Foundation
Families of S.M.A.
Family Voices
Federal Medicare Agency
Flaghouse Inc.
Florida ADA Leadership Network
Florida Alliance for Assistive Service and Technology, Inc. (FAAST)
Florida Children's Forum/Central Directory
Florida Independent Living Council
Florida Institute for Family Involvement (FIFI)
Florida Spinal Cord Injury Resource Center
Ford Mobility Motoring Program
Freedom Concepts
Gabby's
Guldmann Inc.
Heartspring School
Hewlett Packard
Hoveround Corp.
inMotion Magazine
Invacare
International Broadcasting Bureau
Island Dolphin care, Inc.
JayJo Books
John Hopkins Press
Judge Rottenberg Educational Centers
KayJae Manufacturing Co., Inc.
Learning Strategies, Inc.
Magitek.com, LLC
McDonald's Corporation
Merrill Lynch & Co., Inc.
Metroplex Voice Computing Inc.
Mind Wing Concepts, Inc.
Muscular Dystrophy Family Foundation
MyMedMart, Inc.
National Disability Sports Alliance
National Family Caregivers Association
National Institutes of Health
National Multiple Sclerosis Society
National Perinatal Association
Newhope Generation
New Mobility Magazine
NISH
Ocean Hyperbaric Center
Oxy-Health Corporation
PALAESTRA
Pathways Development Group, Inc.
Perkin Elmer Life Sciences
Possibilities Foundation, Inc.
Prentke Romich Company
Pride Mobility Products Corp.
RESPECT of Florida
Ricon
Rifton Equipment
Ross Laboratories
Sammons Preston
Scooter Lift Mfg Co.
Search Beyond Adventures
Shire US Inc.
SHS NORTH AMERICA
Sigma Tau Pharmaceuticals, Inc.
Social Security Administration Office of Disability
SourceAbility
Southeast Disability and Business Technical Assistance Center
Southpaw Enterprises, Inc.
Special Olympics
Spina Bifida Association of America
Sunrise Medical
Super Duper Publications
SureHands Lift & Care Systems
TASH
Teaching Exceptional Children
The Autism Recovery Foundation
The Center for Discovery
The Disability Resource
The Hali Project
The Liberty Motor Co.
The National Neurofibromatosis Foundation, Inc.
Theradapt
Today's Caregiver Magazine
UCP (United Cerebral Palsy)
United Parents' Syndicate on Disabilities
U.S. Customs Service
U.S. Department of Justice
U.S. Disabled Athletes Fund
Vail Products, Inc.
Vision For Life
Volkswagen of America
WALMART
We Media
WE MOVE
Wheelchair Getaways

Exhibitors at press time

Update on the Treatment of Childhood Movement Disorders

by Anne Kirkland

The variety and complexity of childhood movement disorders have made accurate diagnosis and effective treatment a difficult task for pediatricians and even specialists. Fortunately, in the past few years, research in the field has given rise to new treatment therapies available for specific conditions. These therapies have often improved considerably the quality of life for children affected with movement disorders.

Since differences between spasticity and other movement disorders are sometimes subtle, making a correct diagnosis can be difficult—particularly for nonspecialists. Even specialists find it beneficial to compare notes with colleagues. A multidisciplinary team—a neurologist, pediatric neurosurgeon, pediatric physiatrist, orthopedist, physical therapist, occupational therapist and a social worker—comes together in a single clinic to examine the child in turn and arrive at a group diagnosis.

For individual patients and their families, the advantages of such a team approach are tremendous. Instead of going from doctor to doctor, in a process that can involve months, if not years, and multiple misdiagnoses, the doctors all come to the patient. Within a few hours, the entire team has met with the child, deliberated and jointly recommended a diagnosis and treatment plan. Beyond the obvious convenience and cost benefit of this approach is the added value of a diagnosis more likely to be accurate. In an area where distinctions between one disorder and another are difficult to pinpoint, or where combinations of disorders may be present, the team approach promises a more comprehensive process.

Chief of pediatric neurosurgery at Children's Hospital of Pittsburgh and professor of neurosurgery at the University of Pittsburgh, Dr. A. Leland Albright directs the Spasticity and Movement Disorders Center at Children's Hospital. "[Movement disorders] are frequently misdiagnosed because there is not enough awareness of the differences in the disorders," says Dr. Albright. "Some people have mixed movement disorders. They'll have a combination of spasticity and dystonia, or chorea and athetosis. And unless one is aware of the different movement disorders and sees a broad spectrum of kids who have CP, one often thinks that every child with CP has spasticity."

The Spectrum of Pediatric Movement Disorders

Perhaps one reason why other movement disorders are often misdiagnosed as spasticity is because it is by far the most common movement disorder. Approximately 65 percent of people with cerebral palsy (CP) and many people who sustain traumatic brain injuries each year develop spasticity.

Spasticity, a condition that causes stiff, tight muscles, especially in arms and legs, may make movements jerky or uncontrollable and interfere with gait, movement and speech. Spasticity is usually caused by damage to the area of the brain or spinal cord that controls voluntary movement. In a person suffering from spasticity, the brain sends fewer messages to the muscles to tell them to relax. The disorder can also occur in people who have suffered a stroke, have multiple sclerosis, spinal cord injury or certain metabolic diseases.

The degree of spasticity varies from slight muscle stiffness to severe, painful and uncontrollable muscle spasms that may be triggered by a simple movement of the arm or leg, or something as minor as skin irritation or a full bladder. Other symptoms include exaggerated deep tendon reflexes (a reflex within the body), scissoring (involuntary crossing of the legs) and fixed joints. Spasticity can be painful, especially if it pulls joints into abnormal positions called contractures. Contractures develop when a muscle is not regularly stretched or put through its full range of motion. Muscle tendons shorten, making subsequent stretching of the muscle more difficult and leading to further decreases in range of motion. The affected muscle may develop fibrous scar tissue, limiting its range of motion even further. If untreated, contracture can lead to permanent and often painful abnormal postures.

Dystonia is a neurological movement disorder characterized by sustained muscle contractions that result in twisting and repetitive movements or abnormal postures. According to the Dystonia Medical Research Foundation, it is the third most common movement disorder after Parkinson's disease and tremor, affecting more than 300,000 people in North America. Dystonia also affects 25 to 35 percent of people with CP. Dystonia can affect any part of the body, including the arms, legs, trunk, neck, eyelids, face or vocal cords. Though the exact cause of dystonia remains unknown, researchers believe it is due to abnormal functioning of basal ganglia, which are deep brain structures involved in the control of movement. Dystonia can be inherited, but certain forms can be attributed to outside factors, such as CP, exposure to certain medications, trauma, toxins, infections or stroke.

Since there is no laboratory test to confirm a diagnosis of dystonia, it is crucial for the individual who has dystonia to be evaluated by a doctor who is familiar with and able to recognize the characteristic movement. Correct diagnosis depends on a physical and neurological examination and on information taken from the patient.

Athetosis and **chorea** each occur in approximately 5 to 15 percent of people with CP. Athetosis is characterized by slow writhing motions of the arms and hands. Chorea is characterized by brief, rapid, jerking movements that may involve the whole body and have been described as "dancelike."

Ataxia is a movement disorder that affects an estimated 150,000 people in the United States. Hereditary and sporadic ataxias are a group of neurological disorders characterized by a lack of coordination while performing voluntary movements. The movements of people with ataxia may appear disjointed, jerky, clumsy, inaccurate or unstable. Hereditary ataxia affects the cerebellum and spinal cord and is passed from one generation to the next through a defective gene. Some five percent of people with CP have ataxia.

Sporadic ataxias are also common, occurring spontaneously in individuals with no known family history of ataxia. In these cases, ataxia may be due to environmental toxins or medical conditions such as tumor or stroke. The earliest symptoms of ataxia are unsteadiness or clumsiness. Because ataxia destroys both nerve and muscle cells, the disease is progressive and eventually affects an individual's ability to walk. Vision and speech, and in some cases hearing, may also be affected.

Tremor occurs in Parkinson's disease, dystonia, multiple sclerosis and CP. According to the National Institute of Neurological Disorders and Stroke, tremor is defined as a rhythmic, shaking movement of a part of the body caused by muscle contraction. Tremor is the most common of all involuntary movements, variously affecting the head, face, vocal cords, trunk, legs and especially the hands.

Treatment Options

A wide range of treatments is available for patients with movement disorders, including oral medications, intramuscular injections, surgical procedures and physical and occupational therapy.

At Dr. Albright's Spasticity and Movement Disorders Center, the team's evaluation of the patient is critical to the process of arriving at the right treatment plan. Treatments vary according to the patient's age, physical condition and the nature of the movement disorder, and may include one or a combination of treatment options.

Oral and Injected Medications

Oral Medications: The four oral medications most commonly prescribed to treat spasticity are baclofen, dantrolene, tizanidine and diazepam. Most of these medications have been used for the past 20 years and are, in general, mildly effective. However, moderate or severe spasticity is almost never completely eliminated by oral medications. Movement disorders other than spasticity are often treated with different oral medications such as clonidine, trihexyphenidyl or carbidopa-levodopa. For about one third of children who have athetosis and chorea, oral medications such as baclofen, clonazepam, diazepam and propanolol are helpful.

The Dystonia Medical Research Foundation gives a comprehensive list of oral medications available for people who have dystonia. These include drugs that impede nerve impulses (called anticholinergic drugs) such as trihexyphenidyl, benztropine or ethopropazine, which work by blocking the action of acetylcholine, a neurotransmitter that activates muscle contractions. Dosage is usually governed by the severity of the side effects, which may include confusion, drowsiness, hallucination, personality change and memory difficulties. Benzodiazepine drugs such as diazepam, clonazepam and

continued on page 46

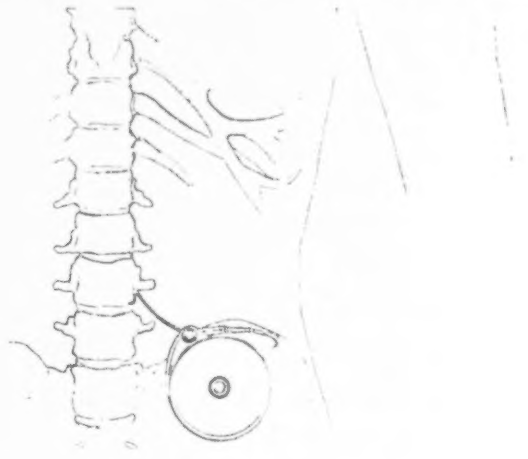
continued from page 45

lorazepam are also used to treat dystonia. The primary side effect is sedation, but others include depression, personality change, and drug addiction. Some dystonia patients may tolerate very high doses without apparent adverse effects.

Intramuscular injections are a treatment option for children who have focal spasticity or dystonia. Intramuscular injections are given to patients to decrease spasticity in specific muscles. The advantage of this form of treatment is its localized effects. The medications weaken only the injected muscle and rarely cause any kind of central nervous system side effects. Botulinum toxin has become available in the past decade and is now frequently used for this purpose. Seven subtypes of botulinum toxin have been isolated, each with different properties and actions. Of these subtypes, botulinum toxin type A, available as Botox, is currently the most studied and most widely used. Botulinum toxin type B is approved by the U.S. Food and Drug Administration (FDA) for treatment of cervical dystonia (spasmodic torticollis).

The dose of botulinum toxin varies according to the size of the muscle injected and the severity of the spasticity. Improvement usually begins within two to three days after the injections and lasts from two to four months. During this period of decreased spasticity in the treated muscle, physical therapists often perform serial casting and begin therapy to increase range of motion. It is important to note that injections of botulinum toxin should only be performed by a physician who is trained to administer this treatment and is familiar with the involuntary movements of the person being treated.

Injections may be repeated several times, although its effectiveness seems to decrease after multiple injections. It has been reported that in some instances a person may form antibodies in response to the complex proteins in botulinum toxin, making subsequent treatments ineffective. One way to minimize the chance that the patient will build up immunity to botulinum toxin is to limit exposure by having treatments no more frequently than every three months.



The Intrathecal Baclofen Therapy is delivered via a surgically placed pump.

When to Consider Surgery

Spasticity-reducing surgery is typically performed for one of three reasons: to improve function, to facilitate ease of care and to reduce the risk of contractures. If improved function is the goal, the team evaluates the child for muscle tone, trunk strength, underlying muscle strength, motivation and ability to comply with therapy. Functional improvements often include improved communication, swallowing, activities of daily living and mobility. Surgery will also be considered if the outcome will facilitate care and help make the activities of daily living easier for the caregiver. In these cases, the team looks at how difficult it is to dress, toilet, feed, position and transfer the child for whom surgery is being considered.

At the same time, it is important to know that surgical treatment is not recommended for everyone. Some patients are too young or too small to be appropriate candidates for surgery, while others are effectively treated by oral medications or alternative therapy. When appropriate, a patient can be reevaluated after a specified period of time.

Surgical Options

Orthopedic surgery can correct or prevent the muscle and bone deformities that are caused by spasticity, but it does not directly change the spasticity itself.

Surgery is recommended for children at least 5 years old, but the best outcomes for surgery result when a child has developed a stable gait pattern, which many consider to occur after 7 years of age. By this age, a child with spasticity has probably undergone other treatments. Surgery is often utilized if these prior treatments no longer seem effective.

The most common orthopedic surgeries are tendon lengthening or release, tendon transfer and osteotomy.

Tendon lengthening or release is a procedure in which the tendon part of a particular muscle is divided into

continued on page 48

Glossary of Movement Disorder Terms

Ataxia: a group of neurological disorders characterized by a lack of coordination while performing voluntary movements.

Athetosis: a movement disorder characterized by slow writhing motions of the arms and hands.

Baclofen: An antispasmodic drug administered orally or by means of a surgically placed pump to reduce spasticity throughout the body.

Botulinum toxin: Any of several nerve toxins derived from the bacterium Clostridium botulinum, which are injected into muscles to permanently reduce spasticity.

Botox: The commercial name for a medication made from botulinum toxin A.

Chorea: A movement disorder characterized by jerky, arrhythmic, "dancelike" movements that may involve the whole body.

Contracture: Abnormal, painful joint positions caused by spasticity in the surrounding muscles.

Deep brain stimulation: An experimental treatment for CP-related tremors and dystonia in which an electrode is implanted in a specific area of the brain that adjusts movement.

Diplegia: Excessive stiffness usually in all limbs, but greater stiffness in the legs than in the arms.

Dystonia: A neurological movement disorder characterized by sustained muscle contractions that result in twisting and repetitive movements or abnormal postures.

Focal spasticity: Spasticity localized in one area of the body.

Generalized spasticity: Increased tone or contraction of muscles, causing stiff and awkward movements.

Hemiplegia: Paralysis of one side of the body.

Intramuscular: Within the muscle.

Intrathecal baclofen: Baclofen that is administered directly to the spinal fluid by means of a surgically placed pump.

Intrathecal Baclofen Therapy (ITB Therapy): delivers Lioresal Intrathecal (baclofen injection), an antispasmodic drug, directly to the fluid surrounding the spinal cord in small, precisely controlled doses using a pump that is placed internally.

Neurologist: A doctor who specializes in the nonsurgical diagnosis and treatment of disorders of the nervous system.

Neurosurgeon: A physician specializing in surgery of the nervous system.

Occupational therapy: Therapeutic use of work, self-care and play activities to increase independent function and enhance development. It may include adaptation of task or environment to achieve maximum independence and enhance quality of life.

Orthopedic surgeon: A physician who specializes in the diagnosis and treatment of injuries and diseases of the musculoskeletal system.

Physiatrist: A doctor who specializes in physical medicine or physical therapy.

Physical therapy: The appropriate use of therapeutic exercise, rehabilitative programs, and physical agents—such as massage, heat, hydrotherapy, radiation and electricity—under the direction of a licensed physical therapist.

Selective dorsal rhizotomy (rye-ZOT-o-me): A surgical procedure in which nerve roots are exposed and tested for function and nonfunctioning nerves are cut to permanently reduce spasticity in selected muscles.

Serial casting: A treatment option using a series of casts to increase range of motion. The casts are replaced weekly or biweekly to progressively stretch the muscles in small increments.

Spasticity: A movement disorder characterized by abnormally high muscle tone, causing stiffness or tightness of the muscles that may interfere with gait, movement and speech.

Spastic quadriplegia: Spasticity that affects both the arms and legs.

Tremor: A rhythmic, involuntary muscular contraction characterized by oscillations (to-and-fro movements) of a part of the body.

continued from page 46

halves and then the ends rejoined to create one longer tendon. This allows greater movement of the joint and less tension on the muscle.

A **tendon transfer** involves detaching a tendon from its original position and attaching it to another site. After surgery, a cast or brace is then put in place for three weeks.

Because bone deformities often occur as a result of muscle tightness, surgery to reposition the bone may become necessary. **Osteotomy** is a procedure that is performed on the thigh bone (femur) to correct alignment with the hip socket. The ball at the top of the thigh bone is cut and repositioned into the hip socket. Sometimes surgery is required on the socket to make it deeper and provide better support for the top of the femur. After surgery, a cast is sometimes necessary but not in all cases.

The long-term results of orthopedic surgery are considered to be better in adults with cerebral palsy than in children with the disorder. These orthopedic procedures are all performed when the patient is under general

Nick and ITB Therapy

From the time 11-year-old Nick Cugini was diagnosed, at 6 months old, with a developmental disorder that was later confirmed as cerebral palsy, his parents, Rob and Eve, had actively researched treatment options. "Nick was seen by a neurologist, an orthopedic surgeon and a physical medicine and rehabilitation specialist, and began a physical therapy regimen. We tried a number of things outside of traditional therapy," Eve recalls. "We were really willing to try things that were not too invasive. Botox was about as invasive as it got. We just couldn't keep up with the spasticity."

Nick, who has spastic quadriplegia, wanted to be able to walk. Instead, in the months leading up to the family' s decision to try surgery, he began to experience a lot of pain and his physical condition regressed. Eve Cugini says, "He was beginning to get into a crouch position, not able to move, and we were up every night with muscle cramps and charley horses." Up until then, Nick had been mobile with a walker, but Eve and Rob worried that he would soon have to go back to using a wheelchair.

Nick' s physical therapist and his physical medicine and rehabilitation specialist, with whom the Cuginis worked most closely, recommended that they consider the intrathecal baclofen pump for Nick—a treatment option the Cuginis knew very little about. Nick' s pediatrician had diagnosed his developmental disorder, but was not knowledgeable enough about CP to recommend treatments. Says Eve, "If his physical therapist hadn't pushed, we probably wouldn't have known (the ITB pump) was out there."

When Nick was 8, he and his parents made a decision that has had a significant impact on the quality of Nick' s life. In June 1999, Nick underwent surgery to receive the Intrathecal Baclofen Therapy (ITB™ Therapy) pump to treat the spasticity caused by his cerebral palsy.

At first, Eve wondered if the ITB pump was the right treatment for Nick. "I knew a couple of children who had been through the process, but they were much more (physically) involved than Nick is. I really needed to see other children who are ambulatory who have been through this process."

The Cuginis weighed the dangers of surgery against the amount of pain Nick was experiencing and his deteriorating quality of life. "The thought of surgery is very frightening," Eve confesses, "but I had a lot of trust in these people who were an integral part of our lives. We started researching the pump and, of course, immediately found out about Dr. Albright." She placed a call to Dr. Albright' s office in Pittsburgh. "They were very generous with us, and even hooked us up with a young adult who had had the pump whom Nick and I could talk to about the difference it had made in his life." Soon afterwards, the family flew to Pittsburgh so that Dr. Albright and his team of specialists at the Children's Hospital could evaluate Nick. According to Dr. Albright, at age 8 Nick was an appropriate candidate for the ITB pump because of spasticity in both his arms and legs.

Nick and brother Alex (l.).

The Cuginis made plans to go ahead with the implant. Eve points out that it is important to schedule surgery in the summer so that the child will have enough time to recover from the surgery and work on building back strength before returning to school. "Nick had the ITB pump implanted in June, spent five days in the hospital, another couple of weeks doing very little, and then began physical therapy with his private therapist."

The difference in Nick' s physical condition was apparent as soon as he woke up from the surgery. "In the hospital anestesia and require a hospital stay of up to five days. Orthopedic techniques can be used in combination with other treatments, such as the selective dorsal rhizotomy, ITB therapy or Botox treatments.

Intrathecal Baclofen Therapy (ITB Therapy): ITB Therapy delivers Lioresal Intrathecal (baclofen injection), an antispasmodic drug, directly to the fluid surrounding the spinal cord in small, precisely controlled doses using a pump that is placed internally. Research by Dr. Albright has demonstrated that ITB Therapy is effective in more than 86 percent of people with severe spasticity, including many who have not had good results with oral medications.

To determine if a patient is a candidate for the baclofen pump, the individual must receive a test dose of the drug so that physicians can study its effects. Once it has been determined by the baclofen trial that there is a successful reduction in muscle tone or dystonia, the patient can have the pump placed. In a procedure that lasts about an hour, the pump is placed in the

continued on page 50

Nick rounding the bases

he was able to lift his arms over his head for the first time in his life," Eve recalls. Now, three years later, Eve reports the results are still positive. "There' s been a significant change in the level of function and the pain. We are never up in the middle of the night with any sort of muscle cramps. He walks with his walker at school and wherever we go, he' s ambulatory."

To maintain the therapy, Nick's physical medicine and rehabilitation specialist in Houston refills the pump every three months, and once a year the family travels to Pittsburgh to meet with Dr. Albright and have Nick checked out. "Fortunately, Nick is on a low dose of baclofen, and there is plenty of room for any dosage increases that may be necessary in the years ahead." Since the pump's battery life is approximately six to seven years, Nick will undergo another surgery to replace the pump when he is about 15. "We are already planning to go forward with that surgery. We have weighed the different aspects and have decided we want to continue using the pump. Nick was really the one who made the decision—from the start, he has always been part of the decision-making process."

Both mother and son are doing all they can to share Nick's success story with others. Since his surgery, Nick has had the opportunity to talk to two other little boys before they had the ITB pump implanted. "He's been able to talk to them and say, 'Don' t be afraid. The doctors are nice, the nurses are nice, you' re going to feel so much better,'" Eve reports proudly.

Eve herself runs a nonprofit organization, the Family to Family Network, which she started because "there's so much information out there and getting information from another family is such a good way to find out about it." The organization serves as a support network for parents in the Houston area who have children with disabilities, and also trains parents to be more effective advocates for their children at school, in the medical community and in the community at large.

Reflecting on the family's experience with ITB therapy, Eve says: "We feel a huge debt of gratitude to Dr. Albright. He has significantly changed the quality of my child' s life. I really want people to know that I understand how frightening the prospect of surgery can be. I also know the difference it has made in my child' s life. It was a summer, and not a huge time commitment. He's out there, he's playing baseball and karate, he' s about to earn his sixth belt in karate, he' s doing so many things that he may not have been able to do had he not had this opportunity."

To learn more about ITB therapy or to locate a center that provides treatment for spasticity, visit www.spasticity.com.

For more information on Family to Family Network contact them at: (713) 466-6304 or via the Web site: www.familytofamilynetwork.org

continued from page 49

abdomen while the patient is under general anesthesia. A catheter runs under the skin from the pump to the back and is inserted into the spinal fluid. The pump is then programmed by an external computer to release continuously a specified dose of baclofen, as determined by the physician. The pump, approximately the size of a hockey puck, comes in two sizes, and needs to be refilled every two to five months, depending on the pump size, concentration and dose. Refills are done using a syringe and needle and take approximately 15 to 20 minutes to complete. The battery in the pump lasts four to seven years, at which time the patient will need to undergo another surgical procedure to replace the pump. The therapy is also reversible.

For patients with functional goals, ITB Therapy reduces spasticity to allow physical therapists to engage them in strengthening programs. Possible risks in use of ITB therapy are mechanical complications with the pump and/or catheter, and chance of infection at the wound site. Adverse effects from the baclofen are usually temporary and may be managed by adjusting the dosage from the pump. Among the most common are headache, low muscle tone, drowsiness, nausea and dizziness.

Selective dorsal rhizotomy is a surgical procedure that helps permanently

Resource Organizations:

The American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)
6300 North River Road
Suite 727
Rosemont, IL 60018-4226
Phone: (847) 698 1635
FAX: (847) 823 0536
Web site:
http://www.aacpdm.org
The AACPDM is a multidisciplinary scientific society devoted to the study of cerebral palsy and other childhood onset disabilities, promoting professional education for the treatment and management of these conditions, and to improving the quality of life for people with these disabilities.

The Child Neurology Society
1000 West County Rd. E
Ste. 126
St. Paul, MN 55126
Phone: (651) 486-9447
Fax: (651) 486-9436
Website: http://www.childneurologysociety.org
The Child Neurology Society (CNS) is a 1300-member non-profit professional association of pediatric neurologists devoted to fostering the discipline of child neurology and promoting the optimal care and welfare of children with neurological and neurodevelopmental disorders. The CNS mission is to ensure and maintain excellence in patient care, education and training, research and advocacy.

Dystonia Medical Research Foundation
One E. Wacker Dr., Ste 2430
Chicago, IL 60601-1905
Phone: 312-755-0198
In Canada: 800-361-8061
Fax: 312-803-0138
E-mail: dystonia@dystonia-foundation.org
Web site: http://www.dystonia-foundation.org
Comprehensive information on dystonia for patients, physicians and researchers, including diagnosis and treatment, healthcare referrals, research and funding opportunities and patient support services.

EP (Exceptional Parent)
65 East Route 4
River Edge, NJ 07661
Phone: 201-489-4111
Fax: 201-489-0074
Web site: http://www.eparent.com
Monthly publication and Web site that provides information, support, ideas, encouragement and outreach for parents and families of children with disabilities and the professionals who work with them. Site visitors can access archived articles from EP by keyword search, learn about new drug research and legislation, and exchange information with other parents and professionals via online forums such as "Search and Respond."

International Tremor Foundation
7046 West 105th Street
Overland Park, KS 66212-1803
Phone: (913) 341-3880 or (888) 387-3667
E-mail: staff@essentialtremor.org
Web site: http://www.essentialtremor.org
Fax: 913-341-1296
The International Essential Tremor Foundation (IETF) was created to provide information, services and support to individuals and families affected by essential tremor (ET). The organization encourages and promotes research in an effort to determine the causes, treatment and ultimately the cure for ET.

Medtronic
710 Medtronic Parkway
Minneapolis, MN
55432-5604
Phone: (800) 664-5111
ext. 280
Web site:
http://www.spasticity.com
Medtronic provides a wide range of products and therapies that help physicians solve the most challenging, life-limiting medical problems and restore health, extend life, and alleviate pain.

The Movement Disorder Society
611 Wells St
Milwaukee, WI 53202
Fax: 414-276-3349
Tel: 414-276-2145
Website: http://www.movementdisorders.com
The Movement Disorder Society provides international forums to disseminate information on recent advances in both clinical

reduce spasticity primarily affecting the legs. During a rhizotomy, the nerve roots in the back are exposed. Each nerve root is tested with special monitoring equipment to accurately detect which ones are not functioning properly. These nerve roots are cut. Rhizotomy surgery generally lasts about two to three hours. Surgery is followed by physical therapy to increase leg strength and improve gait. The primary goal of rhizotomy surgery is often to improve walking; however, the procedure can be done at any age to facilitate care. Its most significant drawback is that its effects are irreversible. It is important to note that a rhizotomy will relieve spasticity but not improve contractures that are already present, nor is it an effective treatment for dystonia, athetosis or chorea. Rhizotomies are recommended for 5 to 10 percent of new patients with spasticity in the arms and legs, and in a higher percentage of those with spastic diplegia.

Deep brain stimulation is an investigational treatment for dystonia approved by the FDA for use with children and young adults (aged 12 to 21) who have failed oral medications and, in most cases, have not responded to ITB therapy. A tiny electrode is inserted into the internal globus pallidus, a small structure deep in the brain that is involved in the control of movement. The electrode is connected by a wire

continued on page 52

and basic science pertinent to movement disorders, encourages research in both clinical and basic sciences related to movement disorders and enhances the education of physicians and the public about movement disorders to support their goal of improving the quality of care of patients with movement disorders.

National Ataxia Foundation
2600 Fernbrook Lane,
Suite 119
Minneapolis, MN 55447
Phone: (763) 553-0020
Fax: (763) 553-0167
E-mail: naf@ataxia.org
Web site:
http://www.ataxia.org

The National Ataxia Foundation is a nonprofit organization established in 1957 with the primary mission of encouraging and supporting research into hereditary ataxia, a group of neurological disorders which are chronic and progressive conditions affecting coordination. There are more than 45 affiliated chapters and support groups throughout the U.S. and Canada.

National Organization for Rare Disorders (NORD)
P.O. Box 8923
(100 Route 37)
New Fairfield, CT
06812-8923
Tel: 203-746-6518
800-999-6673
Fax: 203-746-6481
E-mail:
orphan@rarediseases.org
Web site:
http://www.rarediseases.org

The National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and service.

United Cerebral Palsy (National Office)
1660 L Street, NW,
Suite 700
Washington, DC 20036
Phone: 800-872-5827
202-776-0406
TTY: 202-973-7197
Fax: 202-776-0414
E-Mail: webmaster@ucp.org
Web site:
http://www.ucp.org

UCP's mission is to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities. The national office serves people with disabilities and others through the development of forward-thinking programs, an information and referral service, legislative advocacy, technology initiatives and research. A nationwide network of 111 UCP affiliates in 39 states serves more than 30,000 children and adults with disabilities and their families every day through direct service programs such as therapy, assistive technology training, early intervention programs, individual and family support, social and recreation programs, community living, state and local referrals, employment assistance and advocacy.

WeMove/KidsMove
WE MOVE
204 W. 84th Street
New York, NY USA 10024
Tel: 800-437-6682
Fax: 212-875-8389
E-mail:
wemove@wemove.org
Website:
http://www.wemove.org

WeMove is a comprehensive resource for movement disorder information and education. Since 1991, WeMove has been educating and informing patients, professionals and the public about the latest clinical advances, management and treatment options for neurologic movement disorders.

Kids Move
Website:
http://www.wemove.org/kidsmove

is WeMove's new Web site devoted to pediatric movement disorders. Healthcare professionals and parents may access up-to-date information about the recognition, assessment, treatment, and support available for individuals concerned with childhood movement disorders.

BEST COPY AVAILABLE

SPASTICITY TREATMENT OUTLOOK

METHOD	AGE (YEARS)	APPROPRIATE CANDIDATE	OUTCOME
Oral Medications	Any age; most often 2-5 years	Spastic quadriplegia; Diffuse spasticity	Mild decrease in spasticity in arms and legs Often need SDR or ITB later
Botulinum toxin Injections	Any age; less often over 10	Spastic diplegia; spastic quadriplegia Isolated spasticity Too young for selective dorsal rhizotomy or ITB	Decrease in spasticity injected muscle(s) for 2-4 months Improved walking; sometimes improved arm function
Rhizotomy (SDR)	4 to 8 (most common)	Spastic diplegia or quadriplegia capable of activities of daily living (ADLs) Good leg strength; no severe contractures; motivation for physical therapy Severe leg spasticity; interferes with care	Marked, permanent, non-adjustable decrease in spasticity Improved gait; improved ADLs
Baclofen (ITB)	Enough body mass to support the pump	Spastic quadriplegia; spasticity in legs greater than or equal to spasticity in arms; capable of ADLs Spasticity nterferes with comfort, care ADLS & function	Decrease in spasticity Improved walking; improved ADLs; improved speech; decrease in orthopedic operations; easier care; reversible
OT/PT	Any age	Spasticity of any extremity Spasticity impairs function or reduces range of motion	Increased range of motion, strength, function Improved function or ease of care, minimize deformity
Orthopedic Surgery	Any age, most common over 4 years	Hip dislocations Muscle/tendon contractures Bone/joint deformities	Increased range of motion; improved gait; decreased deformity Depends on goals

continued from page 51

under the skin to a thin electrical stimulator implanted just below the collarbone or in the abdomen. The stimulator is programmed by computer to activate the tip of the electrode to provide quick pulses of electricity to interrupt the abnormal electrical brain circuit that seems to be causing the dystonia. The four-hour surgical procedure to implant the electrode is performed under general anesthesia and the child spends two days in the hospital post-surgery. Currently, Dr. Albright's Spasticity and Movement Disorders Center is the only clinic in the country approved by the FDA to perform this investigational treatment in children. In addition to

FOLLOW-UP CARE	SIDE EFFECTS; RISK	COST ESTIMATES
PT, OT as needed	Drowsiness	Medications= $40 - $60 (each month)
PT, OT to increase range of motion and to increase strength	None with usual doses	Procedure: injection(s)= $250-$400 Medication each time, cost depends on dosage= $400 - $800 (every 3-4 months)
Extensive PT, OT decrease in orthopedic operations	Infection: 2% Wound: 1% Spinal fluid leak: 3%	Hospitalization and surgical procedures= $20,000-$25,000 Intensive PT during first year= $10,000 - $25,000
Frequency of PT, OT depends on goals	Infection: 5-10% Wound: 5-10% Spinal fluid leaks: 5-10%	Hospitalization,implant procedure, pump = $25,000 - $30,000 Initial medication = $400 Medication refills (3-5/year)=$200 - $300 Pump replacement: repeat hospitalization and procedure every 4-7 years
Depends on goals, motivation	None	$100-150 per treatment session
PT, depending on goals	Infection 25% Bony non-unions 25%	$20,000 or more

studying its uses for dystonia, the team has used deep brain stimulation to successfully treat tremors related to CP.

Other Therapies

Physical and Occupational Therapy: Gentle stretching and range-of-motion exercises, as prescribed by a physical therapist, are important adjunct therapies for people with CP and those with dystonia. Stretching and strengthening exercises are especially important in preventing or limiting the permanent muscle shortening caused by contractures. Contractures may also be treated with serial casting to allow tendons to stretch.

The metabolic disorders that cause

continued on page 55

Brigid's rhizotomy

by Kathleen Mason

My husband Greg and I are the parents of Brigid, who is 16 and has cerebral palsy. She uses a power wheelchair for mobility. Since she was diagnosed with CP at the age of 6 months, she has been receiving physical, occupational and speech therapies. Brigid had a rhizotomy when she was 2 years old.

Brigid Mason above and at left on stage performing with the band.

Before the rhizotomy, spasticity would cause her to sit in the "W" position and made her legs scissor (involuntary crossing of the legs in front as a result of muscle contractures). Spasticity also affected how she ate—she could not eat solids. Brigid was enrolled in an early intervention program where therapists did the usual stretching and strengthening exercises. They were not effective. I remember sitting in on those sessions and saw the physical therapist becoming increasingly concerned about how tight Brigid felt.

They suggested we see a pediatric orthopedic surgeon. The surgeon informed us that a rhizotomy would let Brigid be more comfortable and not as tight as she was before. He felt she was the right candidate and at an age when she won't remember everything—and she doesn't. After his recommendations, he referred Brigid to a pediatric neurosurgeon who performed the rhizotomy. Surgery was followed by six weeks of intensive therapies at a rehabilitation facility.

This surgery and its rehabilitation were not easy, but did give us hope, and ultimately improvement. I had feelings of fear, nervousness and worry. It was two weeks after surgery when I realized we had made the right decision. Brigid had some tightness in her throat due to CP which made it hard for her to eat; she had only been able to eat pureed food. During rehabilitation, Brigid began to eat cheeseburgers and drink chocolate milk. We were encouraged that the surgery had worked.

The rhizotomy alone does not give immediate results; for Brigid, it was the combination of therapy and three other surgeries along with follow-up of intensive therapy. She was still tight in her hips and legs which affected her range of motion and ability to function. Brigid had hamstring/heel cord lengthening at age 3 and hip abductor lengthening when she was 5, followed by home recovery and then a seven-week stay at the rehabilitation facility. Her last surgery, when she was in fourth grade, was to put metal plates in her hips and rotate her femurs. This was followed by intensive at-home therapy by her physical therapist. I stand by our decision to do what we did and when. There was a lot of thought, time and energy that went into the decision.

We were told these efforts would help Brigid live a more comfortable, active and enjoyable life. Now Brigid is 16 years old; I look back and think the doctor was right and am glad of what we did when she was 2. She is not as tight, and that makes her range of motion more effective in daily living skills.

At this point no further surgeries are recommended. Currently, Brigid continues physical, occupational and speech therapies to manage spasticity, receiving therapy services at DuPage Easter Seals in Villa Park, Illinois.

Recently, we had Brigid evaluated by a physical therapist who specializes in therapeutic ways for Brigid to manage her difficulties in breath support to aid in speaking and eating. She also suggested a few exercises for the speech therapist to use during treatment. All her therapists have done an outstanding job! Brigid is getting stronger, speaking more clearly, and growing in her self-confidence.

Living here in Naperville, Illinois, has been great for all three of us. People are getting to know Brigid, not for her disability, but for the good person she is and accept her for that. Brigid is now in her sophomore year at Neuqua Valley High School in Naperville, Illinois. There she is involved in the marching band. She will be confirmed on April 20, 2002, at Holy Spirit Catholic Community Church. Brigid enjoys participating in power wheelchair soccer, bocce ball, recreational sports and Saturday night activities through Western DuPage Special Recreation Association, located in Wheaton, Illinois. Brigid is a hard-working, social, warm-hearted typical teenage person. She has had her difficulties coping with her disability but she has overcome them, which truly makes her an inspiration.

continued from page 53

ataxia may be treated with controlled diets and special medications. If the ataxia is due to a toxin, avoiding the toxin and taking particular anti-toxin measures may be appropriate. Most other causes of ataxia, including hereditary forms of ataxia, do not have specific treatments, and there is no replacement for cerebellar cells that die or which never developed properly. The most effective treatment often consists of physical therapy to train and strengthen muscles to compensate for lost function in other muscles. Gait and balance training may also be helpful.

While no single treatment is universal, the range of available treatment options and the potential for combining treatment therapies mean that children with movement disorders now have more choices. They also have a greater possibility of seeing measurable and—in some cases—remarkable improvement in their condition. For more information on individual movement disorders and on different treatment options, consult the resources included here. Also, consider visiting a facility with a movement disorder clinic where a multidisciplinary team is available to make an accurate diagnosis distinguishing between similar conditions and to recommend the optimal therapy treatment. ■

Anne Kirkland is a freelance writer based in the Boston area.

Sources: Dystonia Medical Research Foundation, National Ataxia Foundation, National Institute of Neurological Disorders and Stroke, St. Louis Children's Hospital/ Washington University School of Medicine, University of Pittsburgh Department of Neurological Surgery, WE MOVE.

Putting theory into practice

A. Leland Albright, MD, a nationally renowned expert in the treatment of neurological disorders in children, has performed spasticity reduction procedures since 1985 and has led pioneering research in new treatments for movement disorders. He was the first investigator in the United States to be approved by the FDA to study the use of intrathecal baclofen. Dr. Albright was also the first to perform deep brain stimulation on tremor resulting from cerebral palsy.

The chief of pediatric neurosurgery at Children's Hospital of Pittsburgh and a professor of neurosurgery at the University of Pittsburgh, Dr. Albright directs the Spasticity and Movement Disorders Center at Children's Hospital, a facility that draws referrals from all over the country. The clinic, which currently follows 1,500 patients and evaluates 150 new patients each year, takes a team approach to evaluating and treating children and young adults with spasticity and other movement disorders such as dystonia, chorea, athetosis and tremor.

Dr. Albright describes the team approach used at the center. "There's a multidisciplinary clinic here at the Children's Hospital every Wednesday morning. Children are seen by six different specialists, and after all of us have seen a child, we discuss what we've found and what we think, and put our heads together and come up with what seems in the group's opinion to be the best recommendation."

"We use a lot of oral medicines and Botox, but those are mostly in kids who are 2 to 6 years old," Dr. Albright says. "We recommend rhizotomies for children who are usually 5 to 8 years old, who have good strength in their legs and are ambulatory and are less affected from the waist up. And then we use the baclofen pump for kids who have a lot of spasticity in both the arms and legs and also for those kids who have severe dystonia. For a few others, we recommend deep brain stimulation."

Treatment centers of the future

Dr. Albright's commitment to the study and treatment of movement disorders spans his 25-year career in pediatric neurosurgery. Looking forward, his dream and long-range goal is to have a national center for cerebral palsy treatment and research. "One might think that to have a CP center, just get a bunch of equipment. That is not the case. What we need are people who are committed to doing research, to studying the different kinds of CP, to studying the different treatments." Dr. Albright points out that though two to three children out of every 1,000 born have CP, "very little research is being done in CP."

While centers of excellence exist for pediatric orthopedic surgery in CP, currently no center in the US focuses exclusively on new and experimental treatments for CP. Dr. Albright envisions a comprehensive site providing "state-of-the-art care and evaluation" to treat the spectrum of problems "regardless of whether they are orthopedic, neurological or surgical in nature." Dr. Albright notes, "You can make so many children with CP more comfortable, improve their function or decrease their complications from CP. You can really make some amazing changes in their lives."

For More information

University of Pittsburgh Department of Neurological Surgery
UPMC Presbyterian, Suite B-400 • 200 Lothrop Street
Pittsburgh, PA 15213 • Phone: (412) 647-3685 • Fax: (412) 647-0989
E-mail: info@neuronet.pitt.edu • Web site:
www.neurosurgery.pitt.edu/pediatric/conditions/spasticity.html

Diagnosing and Treating Childhood Movement Disorders

FREE Ask the Expert Teleconference and Web Seminar

http://www.eparent.com

***June 26, 2002 - 6 PM - 7 PM** (EDT)*
(5 PM CDT, 4 PM MDT and 3 PM PDT)

***July 10, 2002 - 8 PM - 9 PM** (EDT)*
(7 PM CDT, 6 PM MDT and 5 PM PDT)

Featuring:

A. Leland Albright, MD

Professor of Neurosurgery, University of Pittsburgh School of Medicine; Chief, Department of Pediatric Neurosurgery, Children's Hospital of Pittsburgh.

Terence Edgar, MD

Associate Professor of Neurology & Pediatrics; Director of Neuromuscular & Movement Disorders Programs, Arkansas Children's Hospital.

Open to Families & Caregivers!

Learn how to differentiate between childhood movement disorders and associated symptoms. Additionally, the experts will discuss available treatment options, outcomes and resources for more information. Following the brief presentation, the experts will be available for questions on-line and via telephone hook-up.

EP Exceptional Parent

UCP Understanding Disabilities Creating Opportunities

Medtronic When Life Depends on Medical Technology

Register online or call today to reserve your place:

Sponsored, in part, by an educational grant from Medtronic, Inc.

Register now for FREE

To register visit www.eparent.com or call 800-EPARENT ext. 203. RSVP by: June 21st 2002
Remember to indicate which program you are interested in.

The events can be easily accessed by telephone and via the Web – through EP's site (www.eparent.com) and the United Cerebral Palsy site (www.ucp.org).

Log on to EParent.com for simple instructions and more details on how to participate.

Circle #50 or visit www.eparent.com/adinfo

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #55 or visit www.eparent.com/adinfo

Positive Behavioral Supports (PBS) for Young Adults:

MEETING BEHAVIORAL CHALLENGES IN COMMUNITY-BASED SETTINGS

By Julie Fodor, PhD, Kimberly Brown Campbell, MA and Celia Flinn, MEd

Greg Larson, a Behavior Consultant at CDHD, helps Dan Skelton complete his Positive Behavioral Supports self-management worksheets.

In greater numbers than ever before, young adults with developmental disabilities and challenging behaviors are graduating from high school alongside their peers. Most would agree that the similarities are remarkable—a new generation of self-confident and accomplished youths with the same hopes and dreams for leading successful independent lives.

Oftentimes, however, this passage into adulthood is overshadowed by uncertainties and worries. Parents of children with behavioral challenges ask: What resources and supports are available in the community? Have all the years of special education adequately prepared my child for successful life experiences in community-based settings? Who will take the role of advocate now to insure that my child's special needs are met?

With the advent and implementation of Positive Behavioral Supports (PBS) in community-based settings in our area, the majority of young adults with whom we work have proven to be capable of experiencing fulfilling lives after high school and becoming active, functional members of society. In addition to maintaining semi-independent- or independent-living situations, these young adults are productively engaged in supported employment, and participate in age-appropriate classes with their peers at day

This article is dedicated in memory of Jean E. Overholt-Emery, MEd, for her many years of service and devotion to the fields of special education and service coordination for individuals with developmental disabilities.

586

treatment centers. They participate in Special Olympics and numerous other community groups.

While many have heard the term Positive Behavioral Supports and are aware that these principles are used increasingly with children who experience challenging behaviors, the concept is relatively new in adult populations within community-based settings. Over the last seven years, our Behavior Consultation Department has experienced a high degree of success using PBS strategies to assist young adults in northern Idaho.

Laura Hart, who will be graduating from high school this year, works on a feeling identification exercise with Greg Larson, a CDHD Behavior Consultant.

The University of Idaho's Center on Disabilities and Human Development (CDHD) in Moscow, ID, provides Behavior Consultation as just one option created for individuals in the state who qualify for Medicaid-funded waiver services. The waiver is designed for adults with developmental disabilities who are working toward independent living within the community. Four Behavior Consultants at the CDHD implement the PBS program that serves two counties.

What are Positive Behavioral Supports?

Positive Behavioral Supports are common-sense approaches to developing person-centered behavioral interventions. They are team-oriented and offer a simplified format for preventing challenging behavior by teaching self-management skills and replacement skills. As a result, they serve as prevention against problem behaviors that might escalate into crisis situations. Ultimately, Positive Behavioral Supports are implemented through the dynamics of team collaboration, individualized therapy and consistent follow-through in community-based settings.

Self-management skills permit young adults to communicate their needs in an appropriate and socially acceptable manner. For example, modeling the behavior of a peer or caregiver teaches an individual how to order dinner at a restaurant; the goal is for the individual to self-manage this behavior and eventually generalize its use in other restaurants in the future.

Young adults respond best to their own specific learning styles; instructors and peers in school and other community-based settings may have already identified them.

How Does PBS Work?

The Center on Disabilities and Human Development Behavior Consultation Department has devised a protocol for use of PBS with people who are transitioning into independent or semi-independent community living situations. Upon an individual's referral to the program, the Behavior Consultant (BC) obtains releases of information, and reviews the individual's personal files and historical data. Then the BC arranges a meeting with the individual's parents or guardians to gather more information and to determine strengths, needs and interests.

Over a period of several weeks before graduation, the individual is observed in school to determine strengths and needs for the future. The BC then interviews parents and teachers to collect more information about

continued on page 60

continued from page 59

the individual's learning styles and previous learning experiences, in order to incorporate existing skills into the new behavior plan.

Young adults respond best to their own specific learning styles, which instructors and peers in school and other community-based settings may have already identified. If a style is not yet established, a variety of techniques can be used to determine which works best, including visual, verbal and/or tactile modes of instruction. We recommend encouraging self-instructional methods whenever possible. Often, self-instruction and self-monitoring receive a warmer reception and foster increased self-esteem and independence. An example of a positive self-instructional method is to have young adults create their own checklists for completing tasks. They can then self-monitor their progress over time with repeated use of the checklist.

Simple strategies are employed to set the person up for success and to encourage positive, self-directed choices that become new habits.

After completing the initial interviews, the BC and parents or guardians form a team and devise a behavior plan that is best suited for the individual's transition from high school to the working world. Jana Schultz, a parent whose son received Behavior Consultation for two years, described the initial transition from high school to the adult world as very difficult. Jana and her son, Toby, wanted the transition process to be a team effort from the beginning. At first, she said, there were few support systems in place and the family felt it was difficult to access services without outside assistance. "There is no way as a parent that you can easily learn what services are out there and access them alone," states Schultz. She believes that families need professionals to help them access resources within the community. Fortunately, with the assistance of his high school special education teacher and his service coordinator, Toby was eventually connected with developmental disability services and the PBS program at the University of Idaho.

Sariah Mackowiak, a program coordinator for a local residential habilitation agency, works with four people who receive Behavior Consultation. She thinks that the biggest advantage of PBS is its ability to teach young adults with behavioral challenges how to self-manage negative behaviors. "It allows young adults to gain independence and promotes more positive social relationships with their peers. These factors help eliminate crisis situations and increase self-confidence, thus naturally reducing behavioral issues," says Mackowiak. PBS helps parents understand how to address behavioral issues they might have struggled with for years. "Behavior Consultation gives new perspectives on how to handle behavioral concerns in the home or out in the community," states Mackowiak.

PBS and Self-Management

PBS supports people with DD in self-managing their behaviors and strives to reduce societal barriers to attaining independence and happiness. While many settings for young adults with challenging behaviors are inclusive or community-based, certain obstacles and stereotypes still undermine the rights and dignity of these individuals. The long-standing "medical model" generally sees the person as the "problem." This approach focuses on "fixing" the individual with a program of consequences and punishment. The medical model in this context is both outdated and potentially harmful.

To fulfill the special needs and desires of individuals with disabilities who experience challenging behavior, it is often necessary to change the environment in which the individual lives and works. "In my experience working with high school students," explains Jerry Hartstein, special education teacher at Moscow (ID) high school, "consistent follow-through of PBS guidelines has had a major positive effect on a student's ability to hold a job and be successful in community-based workplaces."

Hartstein says team collaboration with PBS personnel insures that consistency is maintained in school, home and work environments. When teachers, staff, job coaches and therapists are clear on behavior goals and objectives, students are able to understand and meet expectations. "Ultimately, students reap the rewards. They are happier and can participate more fully in all aspects of their lives in the community," he explained. When discussing students who have benefited from PBS, Hartstein identified Shahna Sprecher, who graduated eight years ago and has been receiving Behavior Consultation for the last six years. "She is doing better than ever out of school," he said.

Shahna, who has Down syndrome, experienced a smooth transition from high school to community-based living.

"It was both challenging and exciting for her," said her mother, Leah. "The supports she received with behavioral issues in high school helped her prepare psychologically to go out into the world of work." Today Shahna receives two hours of Behavior Consultation a week, lives at home with her mother, maintains a part-time job, and attends a day treatment center with her peers. According to her mother, Positive Behavior Supports have been a tremendous help.

Shahna has benefited most by responding more positively to new situations as they arise. She makes eye contact now, and asks for what she needs instead of suddenly running away and compromising her safety. According to Shahna's mother, she is learning responsibility and consistency. "She has learned what to do in order to stick with things. Over the years, personality changes and new social skills have helped her to relate better to others," explains Leah Sprecher.

Behavioral Intervention Plans

Behavioral intervention plans, which are created by the Behavior Consultant with input from the team and family, contain concise, measurable goals and objectives. These plans provide guidelines for practical and attainable implementation. The PBS intervention plan calls for individualized behavioral therapy sessions and application of PBS strategies by both the Behavior Consultant and community service providers.

In the therapeutic setting, instructional methods are highly individualized and cover a broad spectrum of topics. Individual behavior consultation sessions of one-on-one time between the young adult and the Behavior Consultant ideally range from two to six hours per week. Subjects include training in social pragmatics, self-management, problem-solving and communicating emotions appropriately. Other self-management techniques are also taught, to help reduce stress and anxiety or to develop and nurture creative expression.

Multifaceted behavior plans are created, emphasizing the return of control and responsibility to the young adult. Simple strategies are employed to set the person up for success and to encourage positive, self-directed choices that become new habits. Ultimately,

continued on page 62

Exceptional children deserve exceptional care.

The best help for cerebral palsy, spina bifida and related disorders is at Kennedy Krieger Institute.

For 61 years, Kennedy Krieger Institute has been the leader in helping children with severe disabilities. Focusing on early identification, intervention and treatment, our state-of-the-art interdisciplinary team approach—combined with a caring, supportive touch—has enabled generations of children to live their lives to the fullest.

Our comprehensive assessment and treatment for children with cerebral palsy, spina bifida and related disorders includes: Neurology, Medical Services, Nursing, Urology, Orthopedics, Physical Therapy, Occupational Therapy, Orthotist, Clinical Psychology, Neuro-Psychology, Seating, Feeding, as well as Rhizotomy, Spasticity and Movement Disorder clinics.

And unlike many programs, we see patients beyond age 18. Call Kennedy Krieger Institute today. We're here to help.

Kennedy Krieger Institute
707 North Broadway • Baltimore, MD 21205
www.kennedykrieger.org

1-888-554-2080
Kennedy Krieger Institute's Toll-Free Referral Line

Circle #53 or visit www.eparent.com/adinfo

continued from page 61

replacement behaviors shape new worlds for young adults with challenging behaviors by infusing them with unprecedented feelings of self-reliance and self-worth.

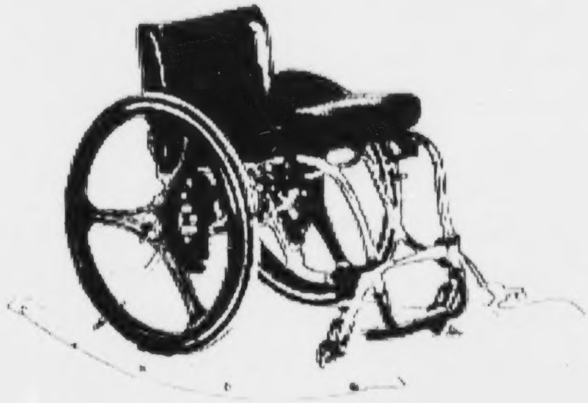
One young man, who experiences learning disabilities and is currently on probation, says he is much happier since he began receiving Behavior Consultation two years ago. "Positive Behavioral Supports have helped me keep out of trouble. During therapy, I have someone to talk to about my problems and figure out ways to resolve them without getting angry. It keeps me focused on my responsibilities," he said. "The monthly team meetings are really helpful and keep everyone on track."

Problem-solving can occur successfully with adults in a verbal, written or pictorial format that provides a narrative and/or visual documentation of a behavioral episode.

PBS Self-Development Techniques

After years of working with adults with developmental disabilities, we noted an area of training that seemed to be most neglected and least understood, a multifaceted component called self-development. In our practice, we have found that fostering self-development through direct therapeutic techniques has proven to be a valuable key to successful and long-lasting outcomes. We have also noted that incidents of challenging behaviors and the need for crisis intervention decrease dramatically by combining team collaboration and ongoing weekly behavioral therapy.

continued on page 65



INNOVATIVE THERAPEUTIC EQUIPMENT

See what a difference *TherAdapt*® can make!

Send for a free catalog!

TherAdapt® Products Inc.

17W163 Oak Lane
Bensenville, IL. 60106
(800) 261-4919 FAX (866) 892-2478

www.theradapt.com

Circle #74 or visit www.eparent.com/adinfo

"Libre Folding Tilt"
with Swing Away Hangers

Introducing the new versatile Spectrum Libre Folding Tilt frame which has the capability to laterally fold, tilt up to 45 degrees and the option of swing away//removable hangers. Any Freedom Designs, Inc. seating mounting hardware can be adapted to this innovative frame. Highlights include: anodized vibrant colors, 75 or 90 degree swing away hanger options, variety of footrest options attached to the frame and backpost mounted armrest options. This versatile frame comes in widths of 10" to 18" and seating depths of up to 20" deep. Let the new Spectacular Spectrum Libre Tilt give you the freedom you've always wanted in a wheelchair frame.

BEST COPY AVAILABLE

FREEDOM DESIGNS
INCORPORATED

www.freedomdesigns.com

2241 Madera Road, Simi Valley, CA 93065 • 805-582-0077 • 800-331-8551

Circle #41 or visit www.eparent.com/adinfo

National Disability Sports Alliance

NDSA

presents...

National Sports Festival® 2002

June 24 - July 1, 2002

Connecticut College

New London, CT

For information, contact: National Sports Festival Office
100 Yound St., East Hampton, CT 06424
Phone/Fax: (860) 267-6757 E-mail: wwilkie100@aol.com
Web Site: national sportsfestival.org

Competition will be offered in the sports of archery, boccia, bowling, cross-country, cycling, powerlifting, track & field, ambulatory soccer and indoor wheelchair soccer, swimming, and table tennis.

Four divisions will be offered:
- *NDSA's Junior National Championship and Adult National Championships
- *WS/USA Junior National Wheelchair Championships
- *International Paralympic Committee for powerlifting
- *A junior and adult division open to all athletes with physical disabilities

BEST COPY AVAILABLE

® Registered trade mark of the United States Olympic Committee

continued from page 62

Self-development serves as an umbrella under which these PBS skill areas of self-management are found: problem solving, expression of feelings and emotions, social pragmatics and self-management of daily living skills. Below we present samples of four of the techniques we have used successfully. Other techniques we have found to be successful for young adults and their families include positive self-talk, stress reduction techniques and creative exploration through the arts.

PROBLEM-SOLVING

A key element in problem-solving is getting the young adult's input in whatever fashion necessary and encouraging his/her proposals for solutions. Problem-solving can occur successfully with adults in a verbal, written or pictorial format that provides a narrative and/or visual documentation of a behavioral episode. If a written review is used, the parent or BC can follow it with a problem-solving discussion if warranted. The discussion should outline techniques for self-management, and offer helpful suggestions for coping with a similar problem in the future. Problem-solving in this manner encourages a repertoire of new skills to resolve internal and external stressors and conflicts appropriately.

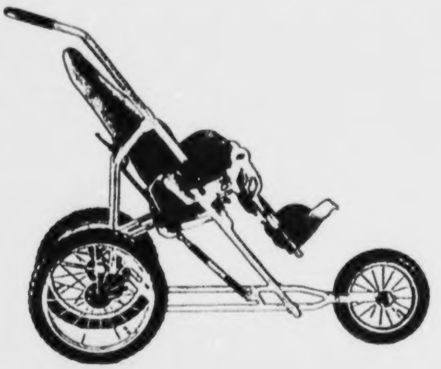
PROBLEM-SOLVING: THINGS TO REMEMBER

- Respond quickly if crisis behaviors occur.
- Interview individuals who were present at the occurrence of the challenging behavior.
- Use a communication format that works best for your child and the team (verbal, written, visual).
- Use the creative process to solve problems.
- Involve your son or daughter as much as possible in the problem-solving process.

FEELINGS AND EMOTIONS

Most of us agree that stress, psychological conflict and/or an inability to express negative feelings have an unhealthy impact on us. Inhibiting emotions or failing to discuss a stressful event is a common occurrence. A Positive Behavioral Supports program can address the cause-and-effect relationship between

continued on page 66



Nothing like smoothing out a few of life's rougher roads.

Now you and your child can take a road less traveled with the EASyS Jogger, and really enjoy the ride.

With the ergonomic Balance Safety System (BSS®), plush padding and spring suspension, the rugged EASyS Jogger smooths out every rock and rut in its path.

And to make life even smoother, you can easily use your standard EASyS Stroller Seating System (size 1) in the EASyS Jogger.

Go where life takes you. Test jog one today, and create your own beaten path.

The EASyS Jogger. Only from Thomashilfen and Bodypoint Designs.

Thomashilfen EASyS BSS
Distributed by
BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #23 or visit www.eparent.com/adinfo

continued from page 65

the occurrence of challenging behaviors and expression of emotions. Thus, preventive measures and solutions can be developed for the person in transition from high school to the adult world.

Fostering self-awareness through talking, writing or creating an artistic rendering of concerns and problems can help individuals feel better about themselves and reduce anxiety. In addition, we have seen encouraging results when teaching problem-solving, coping skills and self-management techniques simultaneously with the "feelings" work.

FEELINGS AND EMOTIONS: THINGS TO REMEMBER

- When left unexpressed, negative feelings and emotions can contribute to illness, accidents and challenging behaviors. Teach your child about the wide range of feelings and emotions.
- Help the individual understand the differences among feelings. Teach ways to express an emotion appropriately.
- Encourage people to express their emotions by talking, writing, using sign language or drawing pictures of what they are feeling.
- Help your young adult to discover the intent of the potential conflict and find positive alternatives for expressing stress and anxiety.
- Provide a safe opportunity for self-disclosure of feelings and emotions. Take time out to discuss these important issues as often as possible.

Social Pragmatics

Social pragmatics are social skills or interactions between speaker and listener that use words or expressions in a social context. Social pragmatics use experiential training to instill new concepts and are often highly successful in supporting the generalization of material.

SOCIAL PRAGMATICS: THINGS TO REMEMBER

- Use consistent, respectful and very specific feedback.
- Use role modeling in community-based settings in which social pragmatics are to be developed.
- Encourage self-management skills and inclusion in society. Skill areas are individualized and may include main-

PERSONAL INDEPENDENCE

THE EVERGREEN CENTER prepares students to lead meaningful lives in the community. Through an individual educational program combining basic skills and behavior development,our students learn to lead more independent lives as integrated members in the community.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631

Serving students with developmental, medical and behavioral needs since 1981.

Circle #37 or visit www.eparent.com/adinfo

Personalized Interdisciplinary Programs

HMS School for Children with Cerebral Palsy serves children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

Physical & Occupational Therapies
Special Education
Speech/Language Therapy
Music Therapy
Communication Aids
Special Medical Attention
Adapted Recreational Activities

Computer Technology
Communication Devices
Environmental Control
Powered Mobility

HMS, founded in 1882, is open to students two to 21 years. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy
4400 Baltimore Ave, Philadelphia, PA 19104
(215)222-2566

Circle #48 or visit www.eparent.com/adinfo

taining eye contact, sitting up straight, developing a well-modulated tone of voice, learning how to read the facial expressions and body language of others accurately and thinking before speaking.

- Feedback is essential and is best given verbally along with a behavioral checklist. This checklist works best when created with the young adult. It should be reviewed before and immediately after the social context in which it is to be used.
- Both positive and constructive feedback should be provided.

Self-Management of Daily Living

In order to develop healthy lifestyles in community-based settings, people must be given opportunities to make personal decisions about the direction in which their lives are headed. Individuals experience an increased sense of autonomy and tend to be more productive and happy when provided predictable and consistent opportunities in which to make choices and self-monitor activities.

STEPS TO SELF-MANAGE ACTIVITIES OF DAILY LIVING SUCCESSFULLY:

1. Make sure the activity is clearly presented and can be initiated at a set time and with a specific behavioral expectation.

2. Use something tangible, such as a behavioral check sheet, for self-monitoring. Your child must be able to see clearly when he or she has accomplished the task at hand.

3. Agree to expectations and a schedule for completion before beginning self-management tasks.

4. Provide an opportunity for self-evaluation and feedback.

5. Use a self-monitoring form to write down areas in which improvement has taken place. Review accomplish-

continued on page 68

southpaw enterprises®
DAYTON, OHIO U.S.A.

Providing Hundreds of Sensory Integration and Development Product Solutions!

Therapists, educators, parents and physicians acknowledge Southpaw as the industry leader in providing high-quality, state-of-the-art and safe Sensory Integration and Developmental products. Our products are made to the strictest standards of quality. We also strive to make our products fun while providing you with the innovative and safe solutions you require for great therapy.

Phone toll free:
1-800-228-1698

Or contact us from our website:
www.southpawenterprises.com

Call for our FREE full line product catalog!

Southpaw Enterprises
P.O. Box 1047
Dayton, OH 45401-1047

Circle #70 or visit www.eparent.com/adinfo

The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW

- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

–Personalized Power Controller

Made in U.S.A.

Circle #43 or visit www.eparent.com/adinfo

continued from page 67

ments regularly and provide consistent positive verbal reinforcement.

6. Set goals for future activities.

STEPS FOR OBTAINING SERVICES DURING TRANSITION FROM HIGH SCHOOL:

1. Contact your local Developmental Disabilities Program or other state agency (e.g., Department of Health and Welfare or Department of Health and Human Services) to find qualified staff within the community.

2. Obtain additional contact information through the school district's main office, special education teachers or other special resource instructors. School personnel should be able to help with your child's transition and to assist with identifying resources that provide Positive Behavioral Supports or similar programs in your area.

3. Set up interviews to be conducted by you and your child to meet area service providers who would be the best "fit."

4. Upon initial referral, provide historical data about your child's disability to service providers.

5. Outline strengths, interests and needs of your child for service providers before meeting with them.

6. Find a trusted advocate such as a case manager, service coordinator or behavior consultant.

7. Once services are in place, set up regular monthly team meetings to insure consistency and follow-through in community-based settings.

8. Develop a Positive Behavioral Supports intervention plan.

9. Set up weekly sessions for your child with a behavior specialist if needed. ■

RESOURCES

Positive Behavioral Supports for Adults: *A hands-on training manual for Behavior Consultants and other professionals working with persons with challenging behaviors.*

The manual is a practical guide to working with adults with potentially challenging behaviors in an array of settings. Included are detailed instructions for formulating behavior plans, functional assessment of behavior protocols, and 47 reproducible forms for hands-on therapeutic activities. The manual is also helpful for parents as a resource guide. CDHD is offering the manual for half price ($20, including S&H) to Exceptional Parent readers. Please order before August 31, 2002.

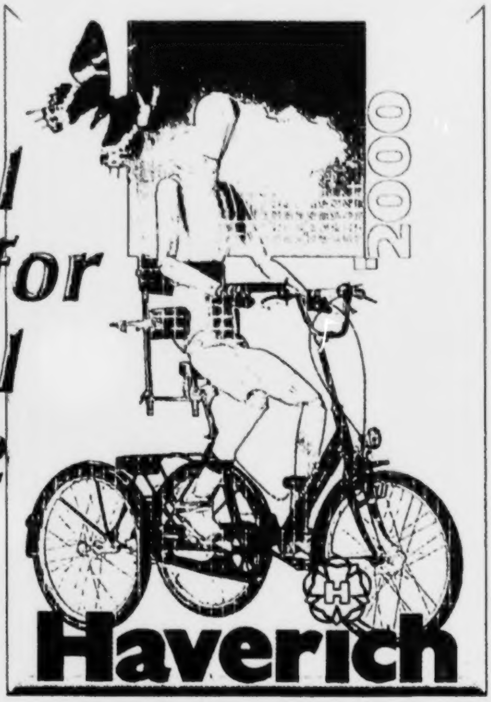
To obtain a copy of the manual or to learn more about Positive Behavioral Supports for adults, contact:

Kimberly Brown Campbell or
Celia Flinn
University of Idaho
Center on Disabilities and
Human Development
129 W. Third St.
Moscow, ID 83843
(208) 885-3554
E-mail: behavcon@uidaho.edu

Julie Fodor, PhD, serves as the Executive Director of the Center on Disabilities and Human Development (CDHD) at the University of Idaho. She is also the Director of the Positive Behavioral Supports project that serves individuals of all ages with challenging behaviors.

Kimberly Brown Campbell, MA, holds a master's degree in art therapy. She currently works as a Behavior Consultant at the CDHD, is an art therapist and administrator at a children's mental health clinic, and maintains a private practice.

Celia Flinn, MEd, has provided clinical services for adults with developmental disabilities for 20 years. She currently serves as the Coordinator of the Behavior Consultation Department at the CDHD.



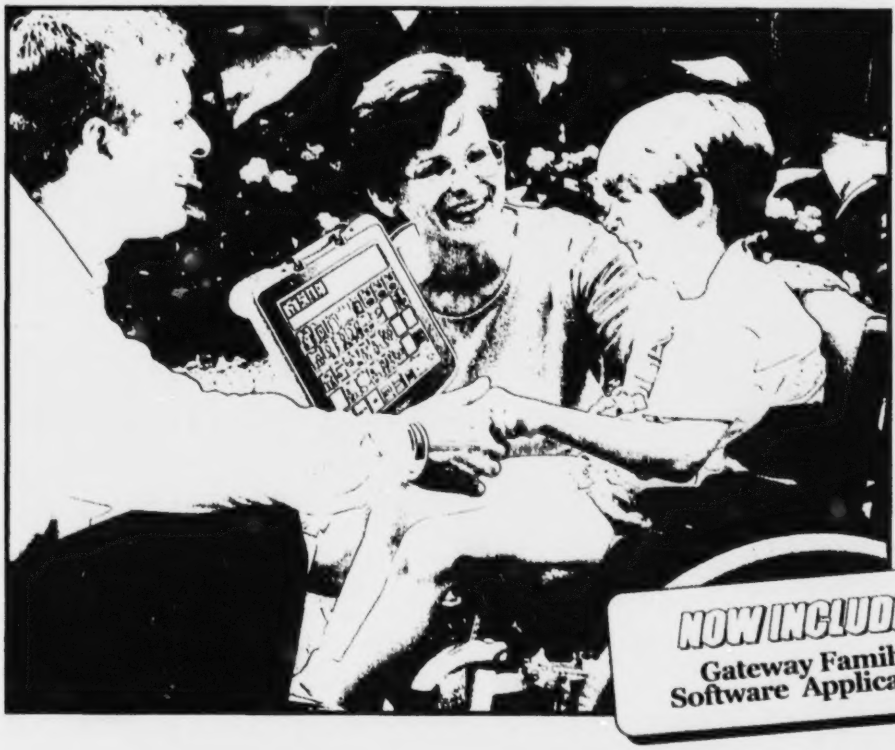
Special Bikes for Special People

A wide choice of bikes, colors and adaptive equipment for people with special needs.

165 Martell Court, Keene, NH 03431
Tel: 603-358-0438 • Fax: 603-358-0453
www.haverich.com

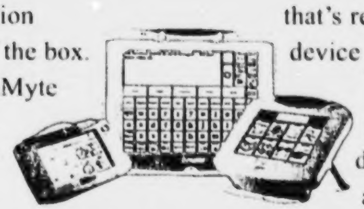
Circle #46 or visit www.eparent.com/adinfo

Communications for Life Just Got a Whole Lot Easier.



NOW INCLUDES...

Gateway Family of Software Applications!



Now even more DynaVox communication solutions are available to you right out of the box. When you order a new DynaVox or DynaMyte communication device, or DynaVox software from DynaVox Systems, you'll now receive Gateway to Language and Learning, Gateway 54 and Gateway Junior, all developed by Joan Bruno, Ph.D., CCC-SLP at no additional cost! Plus, as an added convenience, we will install all three Gateway software programs on the device before it is shipped to you. More communicators will enjoy all the benefits of having a pre-designed vocabulary system that's ready to use as soon as their DynaVox device arrives.

DynaVox products have been helping people to communicate for nearly two decades. All of the professional associates at DynaVox are committed professionals dedicated to preserving dignity and pride...offering compassion and understanding...providing first quality communication products for the ones you love the most.

By making Gateway part of the DynaVox package, we're staying in touch with the kind of communication solutions that professionals want and our customers need.

BEST COPY AVAILABLE

DYNAVOX
a division of
SUNRISE MEDICAL

inTouch *with Communication Solutions for Life.*

For more information please contact our inside sales department at:

1-888-697-7332

www.dynavoxsys.com • e-mail: sales@dynavoxsys.com

Circle #34 or visit www.eparent.com/adinfo

Understanding Transition Services:

A PARENT'S GUIDE

to Legal Standards and Effective Practices

by Gretchen L. Jefferson, PhD and Robert F. Putnam, PhD

Federal and state laws mandate transition service planning for students with special needs who are 16 years of age. Transition services are systematic, purposeful actions that are specified in Individualized Education Plans (IEPs) to prepare and support students with special needs in their transition from the school community to adult community living. The 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA '97), a federal statute with a set of regulations that established guidelines for the delivery of special education services, defines transition services:

> *a coordinated set of activities for a student, designed within an outcome-oriented process which promotes movement from school to post-school activities including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.* (*Code of Federal Regulations* [*CFR*] Section 602.30, Chapter 766)

These activities should be:

> *based upon the individual student's needs, taking into account the student's preferences and interests; and include instruction, related services, community experiences, the development of employment and other post-school adult living objectives and, when appropriate, acquisition of daily living skills and functional vocational evaluation.* (*CFR* Section 602.30)

Under IDEA '97, individuals with disabilities may remain in school until they graduate or turn 22.

What should transition services look like?

Transition services are considered to be a balance of teaching everyday living skills and teaching vocational skills. Several studies report that the unemployment rate for individuals with disabilities after leaving school ranges between 50 and 75 percent. One of the predictors of post-school unemployment is a lack of on-the-job experience while in school. Those students with work-study or paid work experiences tend to have higher rates of employment, better adjustment to the workplace, and higher incomes. Each student's ability to remain gainfully employed and to acquire other critical skills (e.g., social or daily living skills) has a direct impact on successful independent living.

Transition planning prepares students with disabilities to be competent in three skill areas in order to maximize integration into their communities: personal and social skills, daily living skills and occupational and vocational skills. Examples of the skills taught in each of these skill areas are presented below:

How is the transition plan formalized?

The transition plan is explicitly stated in the student's IEP. Because it will be the blueprint for all services, the IEP should be carefully developed. Although IDEA requires that transition services be formally implemented when students reach the age of 16, the student's IEP should be updated annually, beginning at age 14, to contain

This article is a result of a collaborative project of the Commonwealth of Massachusetts Department of Mental Retardation, the Ashburnham-Westminster Public School District and the May Institute.

TRANSITION SERVICES

PERSONAL/SOCIAL SKILLS

1. Maintaining hygiene/ appearance
2. Accepting praise/criticism
3. Situationally appropriate behavior
4. Interpersonal skills
5. Adequate communication
6. Problem-solving skills
7. Decision-making, self-advocacy, self-rights

DAILY LIVING SKILLS

1. Managing finances
2. Maintaining a home
3. Caring for personal needs
4. Buying/preparing food
5. Buying/caring for clothing
6. Recreation/leisure pursuits
7. Community mobility

OCCUPATIONAL/ VOCATIONAL SKILLS

1. Understanding and exploring occupational and vocational alternatives
2. Appropriate work habits/behavior
3. Marketable vocational skills
4. Job-seeking skills

> *a statement of the transition service needs of the child under the applicable components of the child's IEP that focuses on the child's courses of study (such as participation in advanced-placement courses or a vocational program)....beginning at age 16 (or younger, if determined appropriate by the IEP Team), a statement of needed transition services for the child, including, when appropriate, a statement of the interagency responsibilities or any needed linkages.* (*CFR* Section 614)

Transition service needs should be explicitly stated in the IEP as functional, measurable goals and objectives. Goals should target skill areas that are critical to successful transition (social, daily living, vocational). Functional goals and objectives include those that are based on the demands of adult life across a variety of settings. Measurable goals and objectives clearly state the criteria for success or "how far....by when." Here is an example:

	FUNCTIONAL AND MEASURABLE	NONFUNCTIONAL AND NONMEASURABLE
GOAL	The accuracy of Johnny's community banking skills will increase 50 percent over baseline levels.	Johnny will improve his banking skills.
OBJECTIVE	When Johnny makes a purchase using his debit card or checkbook, he will balance his checkbook immediately with 100 percent accuracy across five opportunities.	Johnny will complete banking worksheets with 80 percent accuracy.

To develop functional and measurable goals, begin with the student's present level of performance (PLOP) in all the targeted skill areas. The PLOP must be part of the IEP because it will be the baseline against which all progress will be measured. A comprehensive assessment of the student's skills is needed to determine PLOP. Assessment should include evaluation of performance in social, daily living and vocational skill areas.

Once the functional and measurable goals and objectives have been specified in the IEP, the issue of how to provide instruction in these skill areas must be addressed. To the greatest degree possible, instruction should occur in natural settings, such as a particular job site, grocery store or bank located in the student's community. When selecting these settings, identify and use locations, facilities and job sites that the student is most likely to access post-school. Attending to this detail will help provide a seamless transition when the student has completed school.

continued on page 72

BEST COPY AVAILABLE

continued from page 71

Checkpoint

1. If your child is 14 years of age or older, does the IEP contain a statement of need for transition services?

2. If your child is 16 years of age or older, does the IEP specify which agencies will provide post-school services for him or her?

3. Is it clear from the IEP who is responsible for promoting progress toward transition goals?

4. Review each of your child's transition goals and objectives:

- Are goals stated in functional, measurable terms?
- Is PLOP based on recent assessments and is it clearly stated?
- Are the criteria for success clearly stated?
- Is training set to occur in natural environments (i.e., the community)?

When should you begin to plan for transition?

In deciding when to begin the transition planning process, it is important to consider the number of agencies involved in the student's care and the level of support assumed to be needed through adult life. If multiple agencies are involved in the student's care and you expect this involvement to continue through adulthood, begin transition planning in the early school years. If the student is at risk for dropping out of school or has severe cognitive or behavioral disabilities, it is critical to begin the planning process at an early age.

Some researchers suggest that vocational assessment—a critical component of transition planning—begin in the elementary grades by helping students develop interpersonal and decision-making skills and by ensuring that students have the opportunity to explore vocations and careers. This transition extends into middle school, where initial efforts are made to formally assess the student's interests, aptitudes, work habits, career maturity and development of job exploration and interview skills.

Once the student has reached high school, transition planning focuses on specific job training and obtaining employment, with evaluations of student performance made at the work site and through work samples. The objective of transition planning at the high school level is to promote a seamless transition. In order to ease the transition from high school to community living, students should spend increasing amounts of time in the community as each school year passes. By age 20, transitioning individuals should be settled into living arrangements and employment positions, and be familiar with community activities that they will access at age 22. This goal is accomplished by systematically including individual students in the community from an early point in the educational process.

Checkpoint

1. Is your child currently served by multiple community agencies?

2. If your child is 14 years of age, does s/he regularly participate in vocational activities in the community?

3. If your child is 18 years of age, does s/he hold a work position in the community?

4. If your child is 20 years of age, is s/he settled in the residence, job and community activities to be maintained as an adult?

Who should be involved in the transition planning process?

Families play an invaluable role in the transition planning process: they contribute knowledge of their children, affect their children's values and decisions (i.e., career, residence), and usually have continuous contact with their children throughout the transition. Research has shown that parental involvement is one key to successful transitions; another is student involvement. Students should be invited and encouraged to participate in transition-related activities so that they learn that transition is a process, self-advocacy skills are valuable and priorities and personal vision are important to the transition process.

Checkpoint

1. As parents or guardians, have you regularly attended your child's IEP meeting?

2. If your child is at least 14 years of age, has/she regularly attended IEP meetings?

3. If your child is at least 14 years of age, is a team of educational and community professionals available to assist in transition plan development?

4. What is the transition planning process?

A transition planning team may include any of these people: student; family members; general, vocational and special education teachers, school principal; school psychologist; vocational rehabilitation counselors; occupational and physical therapists; speech/language pathologist; community agency representatives; direct support professionals. A critical component of transition success is student and family involvement throughout the planning process. Nonschool personnel who will be involved with the individual student after s/he exits school should be involved in the process at least two years before that time.

The transition planning process can be thought of as a series of phases: planning and development, implementation, and outcome evaluation. Planning begins with establishment of a transition team, which is responsible for carrying out all three phases of transition. The team's initial task is to develop long-range community-living goals, while giving priority to the interests and preferences of the student and family. Once goals have been established, comprehensive assessments of student needs in all goal areas—social, daily living and vocational—should be conducted in order to determine the PLOP for each. Additional school and community professionals and agencies should be identified for potential involvement in the transition process.

Once all assessments have been completed, hold an IEP planning meeting with all team members to establish functional and measurable goals and objectives. Clearly state in the body of the IEP: what type of vocational experience the student will have; how many hours per week s/he will be working at the job site; the natural environments to be used for training; and which team members are responsible for implementation of training in each of the goal areas.

Implementation of the transition plan is the responsibility of all team members. Remember that, to the greatest extent possible, transition skills should be taught in the environments where students as independent adults will be expected to use them. Throughout implementation of the transition plan, progress toward transition goals should be measured regularly, whether daily, weekly or biweekly. Progress monitoring will provide team members with the information needed to adjust instructional programs to ensure that the student is progressing at a rate that will meet the annual transition goals. Alterations in goals may include a change in the level of support given to the student, especially in the area of employment; for example, a change may be a move from a sheltered workshop to supported employment, or additional coaching at the current site. Transition goals and objectives also should be adjusted to meet the changing community-living goals of students and their families.

Ongoing data collection on progress toward transition goals allows team members to track progress on a daily, weekly or biweekly basis and is the best way to evaluate

continued on page 74

Changing
Lives
Forever

The Anne Carlsen Center for Children offers a 60-year tradition of residential, therapeutic and educational services on one campus. Our individualized services include care for children and young adults coping with cerebral palsy; orthopedic, vision and hearing impairments; autism, pervasive and other developmental disorders; and many other medical challenges. Our multidisciplinary team can reach out to you by conducting evaluations in your child's home and school setting.

Anne Carlsen
Center for Children
Changing lives forever

Jamestown, North Dakota
Call 1-800-568-5175 or visit our
web site at: annecenter.org

Circle #19 or visit www.eparent.com/adinfo

TRANSITIONING

continued from page 73

outcomes. Progress data should be used to change instructional programming, modify existing goals and establish new ones. How quickly and effectively a program adjusts to the needs of a student is an indicator of the quality of the program.

Checkpoint

1. Does my child have a transition team?

2. Do the assessments to be given evaluate areas needed for transition?

3. Are PLOP, functional and measurable goals, responsible persons and time in the community clearly specified in the transition plan?

4. Have outcome measures and the frequency of progress monitoring been specified in the plan?

5. Are we as parents satisfied that this transition plan meets the transition needs of our child?

Effectiveness of current transition services

Programs associated with successful post-school outcomes typically include outcome-based evaluation, inclusion in school and community, community-referenced instruction/curriculum, person-centered transition planning, job placement prior to graduation and family involvement. These services should produce measurable progress during the post-school years in the individual's success in:

- the ability to use community resources such as banks or transportation;
- establishment of employment participation in a social network; and
- independence with lifestyle choices.

Critical components of effective services include the determination of measurable objectives and the assessment of the interventions' effectiveness in achieving progress towards these objectives. Staff working with students in transition will need the ability to develop measurable objectives, and to use data collection and task analytic strategies to determine the efficacy of the interventions provided. Furthermore, standardized adaptive behavior assessments such as the Scales of Independent Behavior-Revised or the Vineland Adaptive Behavior Scale may be conducted on an annual basis.

In order to ensure that students are assisted in reaching the greatest level of self-sufficiency and involvement in their communities, it is crucial to use practices with a documented history of effectiveness. Thus it is recommended that staff working with students with developmental disabilities

continued on page 76

Effective Practice Transition Planning Checklist

Outcome-based evaluation

1. Goals and objectives are written in measurable terms.

2. Data collection systems are in place to measure progress toward each of the goals/ objectives.

3. These data are reviewed at least twice monthly to evaluate progress.

4. Changes are made to instructional strategies or goals as indicated by the data.

Inclusion in school and community

1. Educational activities occur in natural settings.

2. Each year, the time spent in the community increases.

3. Community agencies are active participants in the transition process.

4. Barriers to community living are addressed in the transition plan.

5. People who are 20 years old are living, working and involved in the community activities in which we expect them to be living, working or involved at age 22.

Community-referenced instruction/curriculum

1. Transition plan goals address all areas of need for the transition process, including social, daily living and vocational skill areas.

2. Transition plan goals and objectives are functional.

3. Transition services promote social inclusion and the rights of the student.

Person-centered transition planning

4. Transition plan goals are based on our child's and our family's goals in the areas of social development, daily living skills and job preferences and aptitude.

5. Goals are changed to reflect changes in personal choice.

Job placement prior to graduation

1. Opportunities to learn about future employment options are planned/provided.

2. Jobs students have just prior to graduation are the jobs they are expected to hold at age 22.

3. At age 18 and beyond, our child has an employment position.

Family involvement

1. As parents, we have discussed important transition issues with our child.

2. As parents, we are invited to each planning meeting.

3. As parents, we attend all of our child's planning meetings.

4. Our child attends all planning meetings.

5. Our opinions are solicited and valued at these meetings.

6. The transition plan reflects our input.

Trained staff

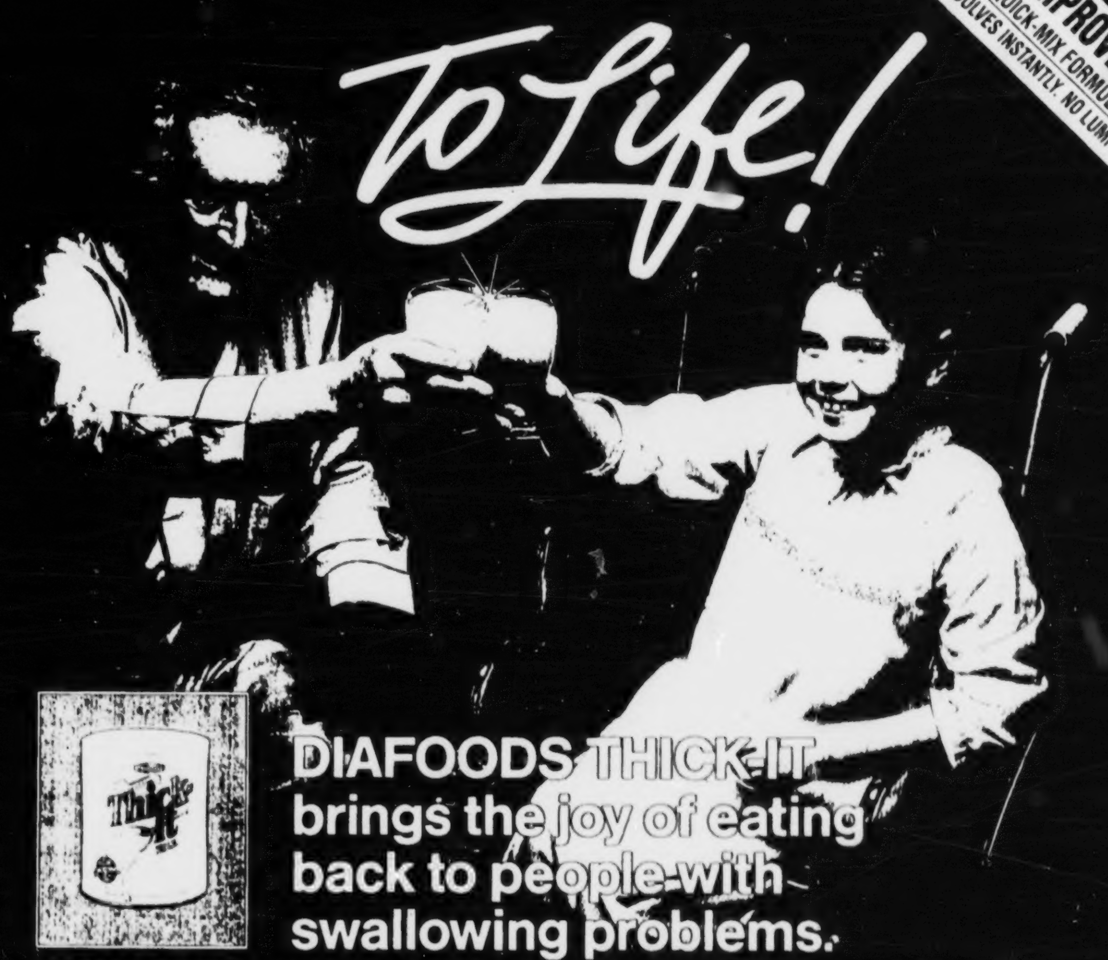
1. Staff training involves both didactic training and case-based—or student-specific—consultation to ensure use of the most effective instructional strategies.

2. Staff are trained in applied behavior analytic procedures.

3. Staff receive an adequate level of training from professionals who are qualified in applied behavior analysis.

4. Staff across settings are trained to promote the generalization and maintenance of skills.

NEW IMPROVED
QUICK-MIX FORMULA
DISSOLVES INSTANTLY. NO LUMPING.



DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

For product literature and advice, a free sample and information where **DIAFOODS THICK-IT** may be purchased, **call... (800) 333-0003.**

Free educational material, call... (800) 333-0003.

The booklet **"Dysphagia, A Review For Health Professionals"** discusses causes, evaluation and treatment of dysphagia.

The pamphlet **"Swallowing Problems"** helps patients and caregivers understand and adapt to dysphagia.

©1996 PRECISION FOODS, INC
2150 N. 15TH AVENUE
MELROSE PARK, IL 60160
TELEPHONE (708) 216-0701
FAX (708) 216-0709

BEST COPY AVAILABLE

Circle #65 or visit www.eparent.com/adinfo

THE DUET
The "Go-Anywhere" Wheelchair/Bicycle Tandem

Enjoy the Great Outdoors like never before!

The DUET is a wheelchair bicycle tandem that allows friends and family to go for a ride in comfort and style. The ergonomic seat is relaxing and allows safe supervision in front. Wheelchair separates for use on its own and for transporting. Hub gear system is easy to pedal. Optional electric motor available.

You'll see smiles everywhere you go - everyone wants a ride!

Frank Mobility Systems, Inc.
Toll Free (888) 426-8581 • www.FrankMobility.com

Circle #39 or visit www.eparent.com/adinfo

Wheelchair Getaways®
Accessible Van Rentals

We understand your expectations.

We understand your needs.

That's why ***Wheelchair Getaways*** *offers you van nationwide rental services with:*
- *24-hour emergency assistance*
- *Pick up and delivery*
- *Long or short term van rentals*

Nationwide Rental Information:
(800) 642-2042

www.wheelchairgetaways.com

Circle #78 or visit www.eparent.com/adinfo

TRANSITIONING

continued from page 74

develop competencies in the use of applied behavior analytic procedures. Applied behavior analysis is a highly individualized method of instruction based on scientific principles of learning theory. It is used to design student-specific programs that are implemented systematically, evaluated empirically, and introduced within natural environments. It matches teaching and intervention strategies to the unique learning style of each student. Because data are reviewed continually and adjustments are made ad hoc, interventions can remain effective and tailored to the needs of the individual. More than 25 years of research have validated this method as the most effective way for individuals—with and without disabilities—to acquire skills, increase socially useful behaviors and reduce problematic ones.

Students with developmental disabilities do not automatically generalize skills from one setting to another. Research has shown that in order for generalization to occur, it must be programmed; parents and staff across settings will need to be trained in order to help the student acquire skills. Educational services are only truly effective if they produce benefits in other settings and with other people. To increase the student's ability to generalize skills outside the classroom, it is important that teaching occur in a variety of natural settings where the student would use the targeted skills, such as a restaurant, grocery store or bank. Instruction should be community-referenced. This will be vital in determining whether the student has successfully mastered the skill. The acquisition of skills may be enhanced by eliminating the steps needed for generalization.

Effective services promote social inclusion and the rights of young people; students' learning experiences should include instruction in decision-making, self-advocacy, and self-protection and training in their rights.

Effective transition services require extensive staff training to assure that staff use the most up-to-date techniques available. Training should include both didactic instruction and case-based, competency-based consultation, so that staff members develop measurable competencies rather than simply log hours of training. For competency-based training, needed skills are task-analyzed into a checklist. Ongoing training and consultation are provided to reinforce competence in the needed areas. Because individuals with developmental disabilities present extra challenges, professionals who are qualified in applied behavior analysis and have a specialty in the individual's area of presentation should provide staff training.

To evaluate a secondary school's transition services, gather information about a program's success in implementing all of these effective practices. Schools that use the most effective instructional strategies and staff training methods are likely to achieve the most positive, measurable outcomes. *The Effective Practice Transition Planning Checklist* on page 74 may be used to evaluate how closely your child's transition services reflect both legal standards and effective practice.

Resources: For information about how to identify qualified professionals in applied behavior analysis, please refer to *Identifying Qualified Professionals in Behavior Analysis and Behavioral Intervention for Young Children with Autism*, edited by Maurice, Green and Luce. The behavior analyst certification board has a web site, http:\\www.bacb.com.

The May Institute has provided training and consultation to schools in 13 different states across the country in the area of effective social skills, discipline, violence prevention, transition services and developmental disabilities including pervasive developmental disorders. For more information about school consultation services contact www.mayinstitute.org/child_schoolhome.asp.

The May Institute, Corporate Headquarters
One Commerce Way, Norwood, MA 02062
781-440-0400, 781-440-0461 TTY, Fax: 781-440-0401
www.mayinstitute.org ■

Robert F. Putnam, PhD, is Vice President of Consultation and School Support at the May Institute, Norwood, MA. He can be reached at rputnam@mayinstitute.org

Gretchen L. Jefferson, PhD, is on the faculty of Eastern Washington University. She completed this work while a postdoctoral fellow at the May Institute.

This work was supported by a grant from the Massachusetts Department of Mental Retardation and the Ashburnham-Westminster Public Schools.

Never in my Wildest dreams...

"WHEN I FIRST CAME TO CROTCHED MOUNTAIN OVER 10 YEARS AGO, activities that were second nature prior to the automobile accident were challenging tasks. Today I am a college graduate and also have my drivers license.

Never in my wildest dreams would I have been able to do half of what I've achieved without the encouragement and help that I received at Crotched Mountain! I want to thank everyone at Crotched Mountain for helping me get my life back!"

—Brent Reagan '93
Crotched Mountain School

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@cmf.org

CROTCHED MOUNTAIN
OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #30 or visit www.eparent.com/adinfo

research reflections

Hooray for Hollywood...

New Feature Film *Pumpkin* Confronts Sexuality and Developmental Disability

by Jan Blacher, PhD

Pumpkin

It's about time the young man with a developmental disability gets the girl! So it plays, as the new feature film *Pumpkin* (United Artists) inadvertently advances a research and policy agenda. *Pumpkin*, which was featured at the 2002 Sundance Film Festival, is scheduled to open in theaters in late June. The film is written by Adam Larson Broder and co-directed by Broder and Tony R. Abrams.

In the film, Jesse Romanoff, a.k.a. "Pumpkin" (played by Hank Harris), is a young adult portrayed as having mental retardation and some physical impairment. Christina Ricci stars as Carolyn McDuffy, a college student whose sorority has adopted the "Challenge Games" (modeled loosely after Special Olympics) as its charity. As part of her volunteer activities, Carolyn begins to work with Pumpkin, who is one of the athletes. Over the course of the movie, Carolyn grows disaffected with her well-built and handsome tennis-star boyfriend, the shallowness of her sorority sisters, and the crudeness with which many of her friends refer to persons with retardation. Meanwhile, her interest in Pumpkin increases; she becomes enamored with his sweetness and apparent goodness in contrast to the jaded and self-serving values of everyone else around her.

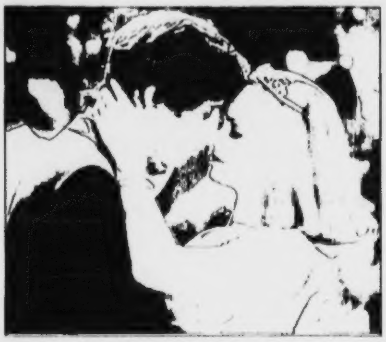
Christina Ricci's performance as an impressionable young woman who is confused, idealistic and driven to "do the right thing" by her emotions and romanticism is highly believable. The relationship between Carolyn and Pumpkin deepens and, eventually, is consummated. There is great awkwardness when they are discovered in bed by Pumpkin's mother, Judy Romanoff (played brilliantly by Brenda Blethain), who feels that Carolyn essentially raped her son.

What distinguishes *Pumpkin* from other Hollywood films (e.g., *The Other Sister* or *I Am Sam*) is that it is not didactic. It does not portray developmental disability as a huge obstacle to be overcome, nor is it painfully saccharine. Rather, the story itself is a dark comedy in which Pumpkin's developmental disability—and how people treat him because of it—acts as a prism through which to view the personality and character flaws of other individuals (who are portrayed in almost-fairy-tale stereotypes).

To place disability and film in context, Stephen Safran, who is a professor of special education at Ohio University, has investigated the frequency of Academy Awards given for Best Picture, Best Actor and Best Actress for films that feature individuals with a disability. In a 1998 paper in *The Journal of Special Education*, Safran cites statistics that demonstrate a dramatic increase in filmmakers' interest in disabilities over the past several decades. In the 1930s, 3 percent of the Academy Awards went to movies involving disability; in the 1990s, 44 percent of the awards did so. The most common disabilities portrayed in films are psychiatric in nature (52 percent), followed by physical disabilities (20 percent) and then sensory impairments (16 percent). Disabilities involving specific intellectual impairment, such as autism, mental retardation or overall developmental disability, are less frequently portrayed, but recent examples include *Forrest Gump* and *Rainman*.

In this growing company of films about persons with disabilities, *Pumpkin* stands out for its complex subject matter. The film not only introduces the viewer to a likable

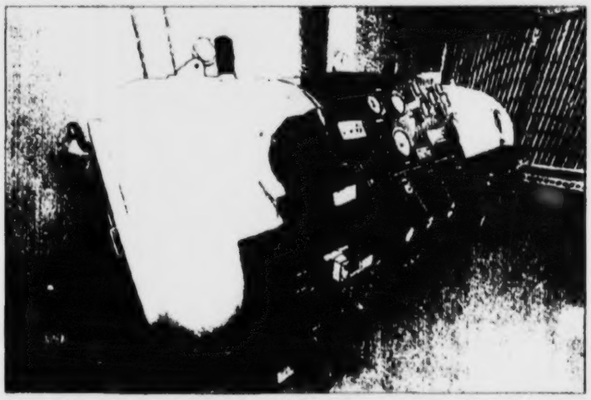
Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, and had been a researcher for more than 25 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of retardation, dual diagnosis and the transition to adulthood. Dr. Blacher has developed **Research Reflections** as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to **Research Reflections** and any suggestions you might have. Send e-mail to: jan.blacher@ucr.edu.



young man who happens to have a physical and a cognitive impairment, but it also confronts unresolved issues around sexuality and disability—a subject few other films have approached.

Sexuality is often denied. One way to deny that sexuality exists is to treat an adolescent or young adult with mental retardation as an innocent child. Ever since Jesse Romanoff was a little boy, his mother referred to him as "Pumpkin," a term of endearment. That she still does it seems inappropriate, yet it is one way she can keep her "little pumpkin" from growing up. Her tone of voice in addressing Pumpkin, as well as her resistance to allowing him any heterosexual encounters, contributes to his infantilization. By failing to consider Pumpkin's chronological age and, to some extent, his cognitive capabilities, and despite overwhelming evidence to the contrary, she can ignore any desire he may have for a sexual relationship and any need he may have for sex education. In addition to Pumpkin's obvious crush on Carolyn, his mother finds him looking at a centerfold in an adult magazine, which suggests that he not only has a

continued on page 80



HYPERBARIC OXYGEN THERAPY

Brain Injuries ~ Cerebral Palsy ~ Near Drowning ~ Stroke ~ MS ~ Lyme Disease

- ✓ Combined 30+ years experience in the hyperbaric field.
- ✓ Care-giver accompanies patient in MULTI-place chambers.
- ✓ NEW chambers with AIR CONDITIONING, entertainment systems and comfortable seating.
- ✓ Experienced Medical Directors are MD's.
- ✓ Facilities are open 7 days/week.
- ✓ Friendly staff makes the experience personal, comfortable, and pleasant.

Two state-of-the-art facilities for your convenience:

Northeast U.S. & Canada
TORONTO HYPERBARIC INC.
Mississauga, Ontario, CANADA
Phone: 905-306-0770
Email: help@torontohyperbaric.com
www.torontohyperbaric.com

Southern U.S.
HyperTec
Olney, Texas, USA
Toll Free: 1-800-218-3588
Email: bbailey@hypertec.ws
www.hyperbaric-health.com

EP neither endorses nor denies the effectiveness of this therapy. For our Editor-in-chief statement see our Contents page.

Circle #75 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

continued from page 79

desire for information about sex, but also knows where to find it.

Denial of sexuality is discussed by Vicki Lumley and Joseph Scotti in their 2001 article in the *Journal of Positive Behavior Interventions*. They cite research indicating that some parents and direct support professionals (DSPs) believe that proactively providing sex education will produce negative outcomes in the form of promiscuous young adults. However, the literature contains decidedly different views on this topic. In their article "Construction of Adulthood and Disability," which was recently published in *Mental Retardation* (2001), Barbara Jordan and Glen Dunlap sensitively consider the rites, roles and rituals of becoming an adult. As Barbara Jordan writes, reflecting on her daughter's sexuality:

> *...I believe equal opportunity is what she would want if she could advocate for herself. I have had significant difficulty envisioning my daughter accessing some of the traditional markers of adulthood. However, the issue is not whether I find it difficult to envision my daughter having sex or getting married, but whether it is something that she may want to do.*

One might well ask why individuals with mental retardation or other developmental disabilities should be held to a higher standard than the rest of the population.

Consider the fact that Barbara Jordan's daughter, Cassandra, is described as having a severe cognitive impairment; in the movie, Pumpkin's level of intellectual ability hovers just around the threshold for diagnosing mental retardation. Though his observable behaviors closely resemble those of his "typical" peers, his mother's longing to protect him produces an overly restrictive home environment.

Sexual consent is a murky concept. There will always be a struggle to achieve balance between protecting individuals with intellectual disabilities from harm and restricting their access to sexual activity. In a review of *Pumpkin* published in the *New York Post* (January 16, 2002), film critic Lou Lumenick states that the movie raises "questions about the athlete's sexuality and whether he's capable of informed consent [...] making some viewers uncomfortable." Clearly, Mr. Lumenick squirmed in his seat, even in light of the carefully placed evidence of Pumpkin's capacity for sexual consent. When Mrs. McDuffy asks her daughter Carolyn if Pumpkin had raped her, Carolyn emphatically replies, "It was consensual."

What does the prevailing research tell us about the capacity of persons with intellectual impairment to give sexual consent? Researchers Carrie Kennedy and John Niederbuhl surveyed 305 members of the American Psychological Association on this issue. They administered a questionnaire that contained 56 items, and asked respondents to rate the perceived importance of each item for determining capacity for sexual consent. The researchers determined that the 56 items reflected five broad dimensions: 1) the consequences of sexual activity; 2) essential sexual knowledge; 3) unessential sexual knowledge; 4) safety for self and others; and 5) basic safety skills. Items the psychologists considered most important for determining capacity evaluations included understanding the consequences of one's sexual activity and being able to protect oneself. However, items related to moral dimensions were not rated in the "important" range.

The researchers recognized that criteria for consent capacity vary widely across states. For example, some states require individuals to understand the nature of their sexual conduct and the possible consequences of their actions, as well as to appreciate the moral dimensions of their sexual activity. One might well ask why individuals with mental retardation or other developmental disabilities should be held to a higher standard.

These may be difficult issues to think about for parents of exceptional children; they are difficult for parents to think about vis-à-vis any child! Like Mrs. Romanoff in the film, Barbara Jordan confesses, "I have been neglectful in educating Cassandra about sexual issues."

Researchers, professionals, parents and DSPs need to look frankly and openly at sexuality and disability. We need to try to reach some agreement about supporting healthy sexual expression for persons with mental retardation/developmental disability. Recently, a special interest group on social and sexual concerns of the American Association on Mental Retardation (AAMR) issued a policy statement on sexuality. The overall position is that "every person shall have the right to exercise choices regarding sexual expression and social relationships." Obviously, individuals with mental retardation/developmental disabilities, and their parents and DSPs, need access to education about the associated rights and privileges that support this position. Fortunately, progress is being made on three fronts:

(1) The professional literature contains papers on individualized programming that incorporate sex education, including programming within a person-centered planning framework. However, we need better, published evaluation research on the effectiveness of curriculum programs currently in use, as well as guidelines for their application. In addition, we need more data-based studies that address the understanding of sexuality and consent issues by specific groups of adolescents and young adults with cognitive limitations.

(2) There are excellent examples of appropriate programming currently in use. For instance, the "circles concept" developed by Leslie Walker-Hirsch and associates focuses on the teaching of adaptive skills needed for social/sexual development. Bancroft NeuroHealth, a large service provider in Haddonfield, New Jersey, has a well-developed Social/Sexual Policy and Training Program for continual staff training and ongoing education for the individuals served by this organization.

(3) There are also commercially available materials on the moral, social and legal aspects of sexuality. For example, the James Stanfield Publishing Company has materials on the moral, social and legal aspects of sexuality. They produce training and educational materials on many topics for and about people with disabilities and special healthcare needs.

Since the movie-going public receives a fair amount of its education on exceptionality at the cinema, we look to writers and directors to deliver their material—however creative or fictional—with veracity, honesty and common sense. *Pumpkin* will likely be heralded by persons with developmental disabilities. While it may be dreaded by their parents, they can always tell themselves, "It's only a movie!" EP

Dr. Blacher was the Research Consultant for Pumpkin, and was a participant at the screenings and press conferences on the film at the 2002 Sundance Film Festival.

A list of resources mentioned in this column may be obtained by e-mailing requests to: epedit@aol.com.

Loneliness shouldn't be a side effect of your child's disability.

At Cotting School, boys and girls of all ages and abilities receive countless opportunities to make friends . . . in the classroom, on a field trip, during basketball practice or in physical therapy. As self-esteem increases with each new friendship, talent and personality shine.

OPENINGS FOR YOUNG PEOPLE FOR 2002 – 2003
NEW POSTGRADUATE RESIDENTIAL PROGRAM NOW OPEN

Cotting School— where your child belongs.

For information or a tour, please call
Janine Brown-Smith at (781) 862-7323.
www.cotting.org www.cottinghopehouse.org

Cotting SCHOOL

Cotting School is a 766-approved day school in Lexington, MA for children and youth ages 3-22 with physical, communication, and other challenges to learning.

Circle #29 or visit www.eparent.com/adinfo

Camphill Special School

Children's Village

A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- **Pennsylvania Approved Private School**
- **Waldorf Curriculum (Member of AWSNA)**
- **Both Day & Residential Programs Available**

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236
www.BeaverRun.org

Circle #25 or visit www.eparent.com/adinfo

Liberty Motors

Liberty Motor Company provides affordable, reliable and safe transportation alternatives.

The Liberty Motor Company is dedicated to improving the lives of persons with disabilities, by providing affordable, reliable and safe transportation for individuals with mobility impairments that require the use of a wheelchair or scooter, across the continent.

With Liberty's exclusive dedication to the Ford Windstar, it has been successfully adapting the minivan for wheelchair accessibility since its inception in 1995. Liberty took a unique approach by seeking the advice of those who use wheelchairs, learning what aspects of the vehicle modification were considered to be of priority concern, and which features were preferred to accommodate the varying needs of its customers. After countless focus groups and prototypes, Liberty developed a revolutionary rear-entry passenger van, incorporating vast experiences and expert design techniques. Liberty's passion to provide a better product and service paved the road for other companies to adopt some of these new technologies and business practices, resulting in dramatic overall improvements in the accessible vehicle industry.

The Liberty Motor Company has two main objectives when manufacturing its product. To keep those using its product safe, while preserving a pricing structure that allows Liberty to provide solutions to people with budget limitations. Among the reasons that Liberty chose to exclusively modify the Ford Windstar was its consistent mechanical reliability, and industry-leading 5-Star crash-test rating. These Windstars are not only safe, but offer the same ride and handling characteristics as a standard minivan, providing for a quiet and comfortable journey. The counter-balanced manual ramp system is virtually effortless to use, and requires little training and no maintenance, ensuring many years of trouble-free transport.

The low-floor rear-entry design includes a custom heavy duty suspension for a comfortable, yet durable ride. The option of a high-capacity rear air-conditioning/heating system ensures that all vehicle passengers enjoy a pleasant atmosphere, regardless of weather conditions or geographic location. Liberty's modified Windstars provide capacity for up to 6 individuals, while offering the flexibility to accommodate up to two wheelchair users, providing the ultimate solution to a variety of needs or circumstances.

The manually operated ramp system eliminates the need for maintenance and the risk of breakdowns. All vehicles are built to meet the ADA (Americans with Disabilities Act) standards, and undergo numerous crash-testing and safety approvals, assuring a safe and comfortable ride for all types of mobility devices.

Another strength of the Liberty Motor Company is its dedication to those who have special needs. A new component to be launched on Liberty's website http://www.libertymotorco.com is a detailed database for assistance programs across North America, helping those in need of financial aid for purchases of mobility equipment.

From a commercial perspective, Liberty combines its efforts with the taxicab and paratransit industries toward the goal of improving public transportation for persons with disabilities. Though its grassroots efforts, Liberty is committed to communicating these needs throughout the various levels of government, in an ongoing pursuit to ensure that all communities are properly served with affordable, accessible transportation. Retirement homes have found the addition of Liberty Motor Company vehicles to be a worthy investment. By offering a service that allows its residents to attend appointments on short notice, or simply just to enjoy a day in the local park, options are created that are proven to increase their quality of life.

Liberty has also established itself across North America as a primary supplier of practical, reliable vehicles to special care patients at an affordable price. Liberty's government interaction has helped facilitate an awareness of the needs of the community of persons with disabilities across North America. Liberty has been instrumental in helping to ease restrictions to provide cost-effective vehicles for individuals and the commercial transportation industry across the continent.

Liberty Motor Company is the highest volume supplier of rear-entry accessible vehicles in North America. In developing a high-volume, streamlined operation with an aggressive pricing structure, new opportunities are available to suit almost any budget. By maintaining constant inventory of between 50 and 100 vehicles in a variety of option and color configurations, your choice of the safest, most reliable wheelchair accessible vehicles is simply a phone-call away.

The Liberty Motor Company's unique corporate strategy ensures that it will remain a leader within the industry for many years to come. Its unique advantages in combining high-volume purchasing, streamlined production, direct distribution and innovative sales techniques allow the Liberty Motor Company to continue to break new grounds in the accessible vehicle industry, providing the highest quality, safest and most reliable vehicles, with the lowest pricing in the industry.

This advertising supplement is sponsored and written by participating advertisers. It did not involve the editorial staff of Exceptional Parent magazine ©2002, Psy-Ed Corp.

Imagine...

if all of your other
choices could be this simple

LIBERTY
MOTOR COMPANY INC

Introducing a

zero maintenance

conversion van with wheelchair access

Starting Under

$20,000 US

(Including vehicle and modification)

- 1996-2002 Windstar Models Available (All vans come with brand new conversions)
- Professionally trained staff ready to help you
- The rear-entry design provides for the safest and most reliable wheelchair accessible minivan on the market.
- The Liberty Motor Co modified Ford Windstar looks and drives like a standard minivan, offering a quiet, comfortable ride.
- Money Back Guarantee

BEST COPY AVAILABLE

Circle #56 or visit www.eparent.com/adinfo

1 (888) 578-8886 www.libertymotorco.com

Vantage Mobility International

Vantage Mobility International (VMI) is the world's premier manufacturer of mini and full size wheelchair accessible vans. VMI's purpose is to provide the highest quality products to enhance the lives of the physically challenged. In addition to manufacturing the most reliable products on the market, customer satisfaction, safety and service are of the utmost importance. VMI is proud to have developed satisfied and loyal customers whose lives have been greatly enhanced by the use of their van conversions.

Because safety and reliability are of the highest importance, all of VMI's van conversions are crash-tested and retain the manufacturer's warranty after the conversion. Product offerings include conversions on Ford, Chrysler and Dodge mini vans and Ford full size vans. Mini van conversions include a choice of Northstar, the revolutionary automatic in-floor-ramp system, the Northstar E-Series, a manual version of the Northstar and the Summit, a revolutionary bi-fold ramp system. The Ford full size van conversion includes either an under-the-vehicle or an in-cabin lift.

In addition to van conversions, VMI manufactures exterior power scooter lifts and interior power wheelchair and scooter lifts: the Excel, Excel E-Series and the Outback. The Excel is an inside mounted scooter and wheelchair lift with a 350-lb. lifting capacity and is the only lift to feature a keychain remote control. Coupled with its stylish design, easy installation, and emergency release, the Excel is the fastest growing lift on the market. The Excel fits comfortably in most SUV's, minivans and full-size vans. The Excel E-Series is an economical manual version of the Excel that retains the Excels powerful lifting capacity and stylish design. The Outback is a sturdy exterior scooter lift that fits both 3 and 4 wheel scooters and automatically stows in the upright position. It has a unique design with dual hold down arms, a "stabilizing pin" to reduce rattles and sway and a swing-away option. The Outback's durable anti-slip platform and all-steel, weather-tight construction ensures years of reliable use. All VMI lifts are eligible for reimbursement of up to $1000 from GM, Ford, Daimler/Chrysler, Saturn and Volkswagen, under the terms of their mobility programs.

YouCan HAVE THE BEST

Reliability.

Northstar, America's favorite in-floor ramp system, featuring a 10" lowered floor and 58" of headroom, provides an obstruction-free doorway. With standard One-Touch control, just a single touch of the remote silently deploys this reliable ramp.

True freedom at an affordable price.

ACME Mobility, Inc • 1234 Your Street, Anytown • USA 12345
800.123.4567
Authorized Dealer-Vantage Mobility International

vmi

Circle #84 or visit www.eparent.com/adinfo

Freedom

No matter where you want to go in life, you can get there with the new Kneelvan from Freedom Motors. Only Kneelvan lets you park where you want and when you want. No more blocked side entry lifts or ramps. The seating is best in its class, with seating for up to 7 people, so you can take the whole family along.

You can choose the fully manual Kneelvan or fully automatic remote controlled Kneelvan. Or you can choose the selfdriver option, it comes fully equipped with remote auto entry and a state-of-the-art driver transfer seat for the ultimate in freedom and independence.

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel**. Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #42 or visit www.eparent.com/adinfo

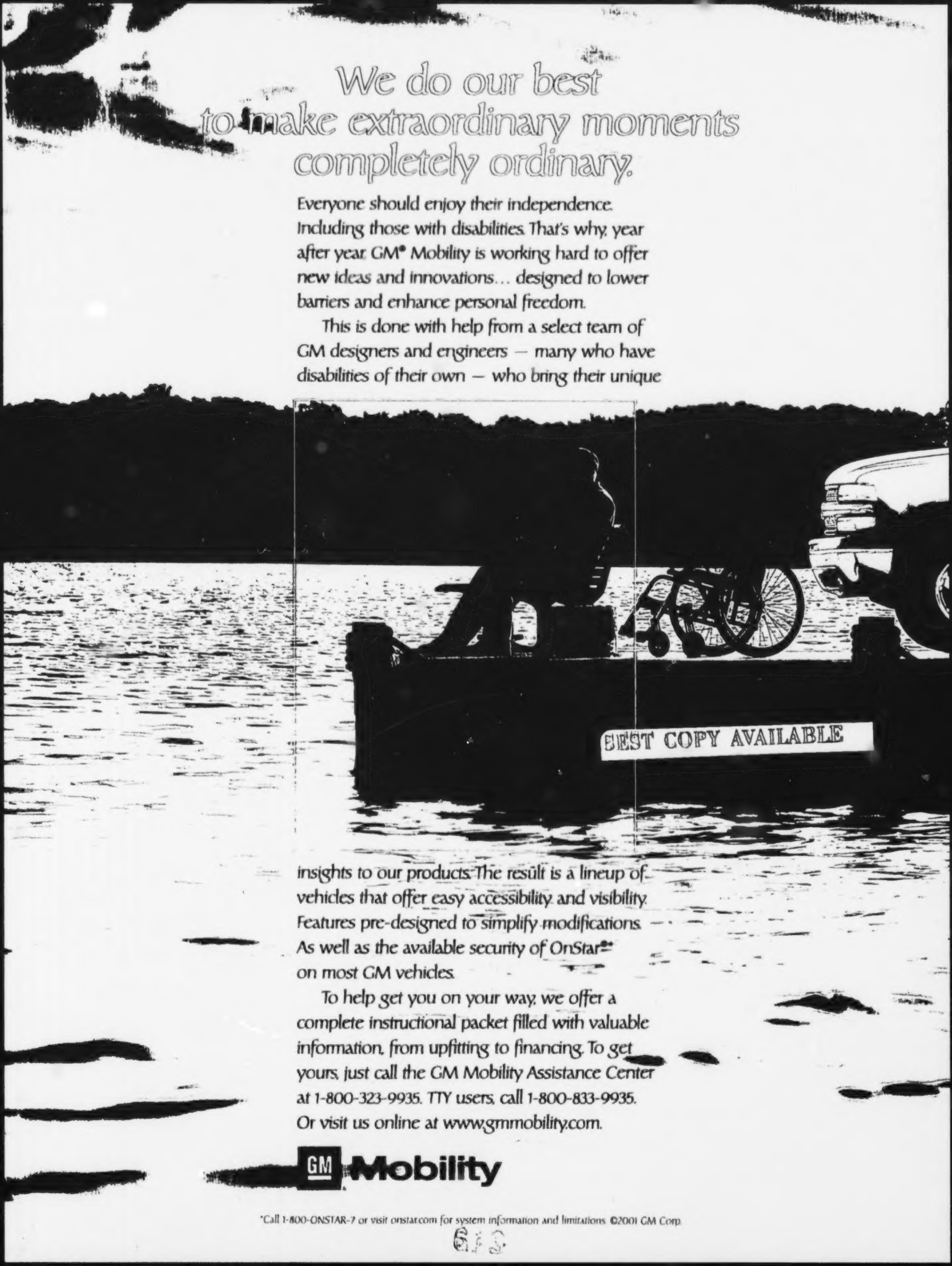
GM Mobility

Dedicated to helping you live life to the fullest

Let your lifestyle choose the best ride for you. You will be pleasantly surprised how many GM vehicles can be adapted by independent suppliers to accommodate personal mobility equipment required by drivers or passengers. We even offer mobility prep options that configure both vans and minivans for aftermarket conversions and save you money. The GM Mobility Program reimburses up to $1,000 toward the actual cost of eligible aftermarket adaptive equipment when installed on any eligible new GM car, van or truck.

For additional information and our new consumer catalog, visit gmmobility.com or contact us at 800-323-9935 (TTY Users: 800-833-9935).

GM MOBILITY℠



Everyone should enjoy their independence. Including those with disabilities. That's why, year after year, GM® Mobility is working hard to offer new ideas and innovations… designed to lower barriers and enhance personal freedom.

This is done with help from a select team of GM designers and engineers — many who have disabilities of their own — who bring their unique insights to our products. The result is a lineup of vehicles that offer easy accessibility and visibility. Features pre-designed to simplify modifications. As well as the available security of OnStar®* on most GM vehicles.

To help get you on your way, we offer a complete instructional packet filled with valuable information, from upfitting to financing. To get yours, just call the GM Mobility Assistance Center at 1-800-323-9935. TTY users, call 1-800-833-9935. Or visit us online at www.gmmobility.com.

GM Mobility

*Call 1-800-ONSTAR-7 or visit onstar.com for system information and limitations. ©2001 GM Corp.

BEST COPY AVAILABLE

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

EMPLOYMENT SYMPOSIUM

October 3, 4, & 5, 2002

In Association with:

Brevard Community College

Family Care Councils

Florida Alliance for Assistive Service and Technology

Florida Association of Rehabilitation Facilities

Florida Children's Forum

Florida Developmental Disabilities Council

Florida Directory of Early Childhood Services

Florida Institute for Family Involvement

Florida Goodwills

Florida Rehabilitation Council

The Family C.A.F.E., Inc.

Georgia Association of Training , Employment and Supports

RESPECT of Florida

NATIONAL SPORTS FESTIVAL FOR THE DISABLED SLATED FOR JUNE

The National Sports Festival for the Disabled, the nation's biggest event for athletes with physical disabilities, will take place June 24-July 1, 2002, in New London, CT, bringing together several hundred athletes with disabilities from approximately 40 states to compete in national championships and open competitions.

The National Sports Festival, a registered trademark of the US Olympic Committee, is affiliated with the National Disability Sports Alliance (NDSA). Both organizations provide competitive opportunities for athletes with physical disabilities, just as the Special Olympics movement provides similar opportunities for people with mental retardation. Athletes competing in the National Sports Festival typically have such disabilities as spinal cord injury, amputation, visual impairment, cerebral palsy and traumatic brain injury. The Festival has drawn international recognition and participation; previously it played host to the US Paralympic Team track and field trials for the 2000 Paralympic Games held in Sydney, Australia.

The NDSA is responsible for conduct and administration of approved sports in the United States. NDSA formulates the rules, implements policies and procedures, conducts national championships in twelve sports, disseminates safety and sports medicine information and selects athletes to represent the United States in international competition. NDSA is a Community Based Organization (CBO) member of the United States Olympic Committee.

The 2002 National Sports Festival will feature two National Championships. First is the NDSA's Junior & Adult National Championships, for athletes ages 7 to adult, with competition in bocce, bowling, cross country, swimming, track and field, powerlifting and indoor wheelchair soccer. The second is Wheelchair Sports USA's Junior National Wheelchair Championships, featuring archery, swimming, table tennis, track and field and weightlifting for athletes ages 6 to 21.

For athletes not competing in the National Championships, open competitions will be held at the Junior level (ages 7 to 18) in bowling, cross country, swimming, track and field and indoor wheelchair soccer. Open Adult Competition includes bowling, track and field and indoor wheelchair soccer.

Open competition in International Paralympic Committee-sanctioned powerlifting will also be held for athletes from all physical disability groups, ages 16 and older.

Competition venues for the National Sports Festival will be the athletic facilities of Connecticut College. During the Festival, competitors and their families will have access to

continued on page 90

Ocean Hyperbaric Neurologic Center

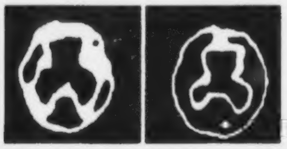
Positive Transitions Resulting from Hyperbaric Oxygenation Therapy

Hyperbaric oxygenation often causes a positive transition for children with cerebral palsy and brain injury. At a symposium sponsored by the Ocean Hyperbaric Neurologic Center last July,* doctors from 14 countries spoke on the benefits of hyperbaric oxygenation in hundreds of children with these conditions. The main transitions were: 1) reduction of spasticity; 2) increased cognitive function; 3) improved fine and gross motor control; 4) improved nutrition and normalization of bowel habits.

At the Ocean Hyperbaric Neurologic Center, we have seen many positive changes take place; some profound. A little boy with microcephaly had his head circumference return to normal (the fontinellas had not yet closed). A three-year old with stroke from umbilical cord around the neck arrived in a wheelchair and was able to run around by the end of treatments. Other children with speech and learning disabilities showed positive transitions approaching normal. Seizure disorders are also treated, and in many cases result in a reduction in frequency and/or severity of seizures, and often anti-seizure medications are reduced or stopped.

As noted previously, transitions from coma, although at times slight, are wonderful for the family and very cost effective.

All of the patients at our center have been validated with functional brain imaging, which measures blood flow and metabolism via SPECT (Single Photon Emission Computerized Tomography) scans. Results from a joint venture with Nova Southeastern Medical School has shown that there is a high statistical correlation between the changes in blood flow produced by hyperbaric oxygen and the clinical condition.



(Red indicates improvement)

* *The entire proceedings of this symposium are available from Best Publications at (800) 468-1055.*

FREE VIDEO & INFORMATION!
CALL (800) 552-0255 OR
EMAIL **info@oceanhbo.com**

OCEAN HYPERBARIC
NEUROLOGIC CENTER

4001 OCEAN DRIVE
LAUDERDALE-BY-THE SEA, FLORIDA 33308

Visit www.oceanhbo.com

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #63 or visit www.eparent.com/adinfo

Crystal Springs School

A PROGRAM OF THE
Institute for Developmental Diabilities, Inc.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeastern Massachusetts, close to Boston, Cape Cod, Providence and Newport, RI.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, Including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availablity.
- Licensed by the MA Office of Child Care Services.
- Approved by the MA Department of Education.
- Member of the MA Association of Approved Private Schools.

For information, Please Call Our Admissions Coordinator:
1-800-840-8087 (508) 644-3101 Ext: 375

Circle #31 or visit www.eparent.com/adinfo

We Like Making Kids Happy ...

Send For Free Catalog

equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094
E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #36 or visit www.eparent.com/adinfo

continued from page 89

social activities featuring the sights and sounds of Connecticut. Major sponsors of the National Sports Festival include Connecticut Institute for the Blind/Oakhill (CIB), The Hartford, Mohegan Sun, U.S. Food Service/Norwich, Hanger Prosthetics and Orthotics and Southern New England Telephone. The National Sports Festival is also supported by the Village Print Shop, Bristol Meyers-Squibb, the Tolland Fund, Inc., SNET Pioneers, Ohio Willow Wood, Hospital for Special Care, Banana Boat and Coca-Cola.

Admission to the National Sports Festival is free for the public. Athletes must be members in good standing of the National Disability Sports Alliance (NDSA) (formerly USCPAA) or Wheelchair Sports USA (WSUSA). Entry fee for athletes is $100 before May 24; after that date the fee is $125.

For more information, contact:
the National Sports Festival at: (860) 267-6757;
Web site: http://www.nationalsportsfestival.org.

Child Health Monitor and EP Form International Strategic Alliance

EP has formed a strategic alliance with ChildHealthMonitor.org (CHM)—a Web-based company in Australia. CHM reviews the most recent issues of the 11 leading medical journals on child and adolescent physical and psychological health from the USA, Europe and Australia, plus the four leading general medical journals from Europe and America. Articles based on their reviews are then posted on CHM's subscriber Web site.

Starting in June, EP and CHM will develop a co-branded Internet channel for families and professionals, where selected articles from CHM's archive will be posted. There will also be special offers from CHM and EP such as discounted bundled subscriptions and book sales. For more information, see the EP Web site, http://www.eparent.com.

S.O.F.T. 2002 CONFERENCE

S.O.F.T. (Support Organization For Trisomy 13, 18 and related disorders) is a nonprofit organization offering support for parents who have had a child with a chromosome disorder, and education for families and professionals interested in the care of these children. Since 1987, S.O.F.T. has hosted an annual national conference; this year it will be held July 10-14 at the Oak Lawn Hilton, Oak Lawn, IL.

To request information about **S.O.F.T.** and the conference, contact:

S.O.F.T.
(800) 716-SOFT(7638)
E-mail: barbsoft@aol.com
Web site: http://www.trisomy.org

616

familiar faces

BENJAMIN

The Tepper brothers, Benjamin (left) and **Matthew** (right) love to be together. Benjamin was born with an undiagnosed genetic disorder which left him with global developmental delays. He receives physical, occupational and speech therapy, as well as special instruction at home. *Teletubbies* is his favorite TV show! His mother Pam reports that Matthew continues to be Benjamin's biggest motivator.

LANCE ALEXANDER

Lance Alexander Humphrey, 10, is a fun-loving little boy who loves concerts, the movies, going bowling and visiting fairs and the mall. He has been in school since he was 2 years old and enjoys it. Lance has cerebral palsy and multiple disabilities, including blindness, scoliosis and kyphosis. He uses a few words and sometimes repeats after his family.

KIM

Kim Hoang is learning to drive her power-chair. Kim has cerebral palsy and enjoys her weekly session of water therapy. She also enjoys spending time with friends. She was born in Vietnam and has lived in the United States for 16 years. Her guardian writes, "Kim is a joy and spreads smiles to everyone she meets."

COLTEN

Colten Conner, 2, enjoys watching TV, playing with his daddy and spending weekends with his grandparents. Colten has microcephaly, cerebral palsy, myoclonic seizure disorder and cortical visual impairment. He lives at home with his parents, Melissa and Mike.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (EXCEPTIONAL PARENT), 65 E. Route 4, River Edge, NJ 07661. (Please do not send originals or "one-of-a-kinds," as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

LEGISLATIVE UPDATE

TICKET TO WORK PROGRAM GETS DOWN TO BUSINESS

Ticket to Work, a voluntary program under the Social Security Administration, hopes to put more people with disabilities to work. Beginning this year, the program will provide people who receive disability benefits (Social Security or Supplemental Security Income [SSI]) with a Ticket that may be used to obtain vocational rehabilitation, employment or other support services from an approved provider.

How the Ticket works

Individuals may take their Ticket to any of the employment service providers—called Employment Networks—who offer services in their communities. A list of participating networks can be found at http://www.ssa.gov/work. Together, the Network and the Ticket holder design an individual employment plan which will assist the Ticket holder in reaching his or her employment goals.

Since the program is voluntary, people who receive a Ticket are not required to work and Employment Networks are not required to accept Tickets. Ticket to Work is intended to give people with disabilities more choices in achieving self-sufficiency and opportunities for finding and keeping a job. The services of an Employment Network are provided free of charge to Ticket holders.

Coming to a mailbox near you

The program will launch across the US and territories in three phases, the first of which began in February. By rolling out the Ticket program in phases, the Social Security Administration will be able to evaluate the program and make any necessary improvements before it is fully implemented. The SSA will hold Quarterly Meetings which will serve as conduits for ongoing evaluation (see below for schedule).

Tickets will mail out based on the last digit of a beneficiary's Social Security number. In the first phase mailing, the Tickets will reach 2.4 million beneficiaries in 13 states—Arizona, Colorado, Delaware, Florida, Iowa, Illinois, Massachusetts, New York, Oklahoma, Oregon, South Carolina, Vermont and Wisconsin.

The second phase, scheduled for late 2002, will initiate Alaska, Arkansas, Connecticut, Georgia, Indiana, Kansas, Kentucky, Louisiana, Michigan, Mississippi, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, South Dakota, Tennessee, Virginia and the District of Columbia.

In 2003, the final phase covers Alabama, California, Hawaii, Idaho, Maine, Maryland, Minnesota, Nebraska, North Carolina, Ohio, Pennsylvania, Rhode Island, Texas, Utah, Washington, West Virginia and Wyoming, as well as American Samoa, Guam, the Northern Mariana Islands, Puerto Rico and the Virgin Islands.

Removing barriers to healthcare

Ticket to Work program is an important part of the Ticket to Work and Work Incentives Improvement Act of 1999. In addition to the Ticket program, the law includes other provisions, such as expanded healthcare coverage. In the past, many people with disabilities had to choose between qualifying for healthcare coverage and having a job.

In effect since October 1, 2000, the law expands Medicaid and Medicare coverage to more people with disabilities who work. States may provide Medicaid coverage to more people who are still working. States also may permit working individuals with income above 250 percent of the federal poverty level to purchase Medicaid coverage. Most people who receive SSI benefits are eligible for Medicaid, a state health benefit. These individuals should contact their state's Medicaid office for more information. Other provisions in effect since January 1, 2001 under the law include expedited reinstatement of benefits for individuals whose coverage ended because of work and deferral of medical disability reviews for individuals using a Ticket.

Open for feedback

The Office of Employment and Support Programs of the Social Security Administration will hold public Quarterly Meetings around the country focusing on issues related the Ticket to Work Program and the Ticket to Work Incentives Improvement Act. The remaining meetings scheduled for 2002 include:

May 14-16 in New York, NY (This meeting will have special emphasis on issues related to youth with disabilities and transition from school to work.)
August 20-22 in Washington, DC
November 13-15 in Albuquerque, NM

For more information or to learn how to obtain a ticket, call the Ticket to Work Helpline toll-free: (866) 968-7842; (866) 833-2967 (TDD). ■

Who will care for your disabled child when you are gone?

**Litigators Incorporated, P.C.
& Affiliated Law Firms**

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

**Check out my web-site at
www.thelitigatorsinc.com**

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

**Call Litigators Incorporated, P.C. NOW!
1-800-LAW-3350**

Circle #57 or visit www.theparent.com/adinfo

3

"Reel Life"

By Roseann Forziano

I see Sean Penn has turned in an Oscar-caliber performance in his new movie *I Am Sam*. I had predicted his nomination just from its one-sentence synopsis in the local paper: "Mentally challenged father fights to retain custody of his daughter." A number of years ago a pre-Oscar broadcast of the *Today Show* featured a reporter from *Variety* setting odds for predicting each contender's Oscar chances. This hip Hollywood type informed us all that "if you play a retard, you get nominated." Although this type of insensitivity deserves an entire essay itself, my immediate concern is a different one.

What prompts me to write now is the portrayal, once again, of individuals with developmental disabilities as sweet, somewhat befuddled, oddly-dressed angels who only need an understanding and well-meaning "normal" person to make their lives into happy imitations of "normal life." I know that I should be grateful that TV and movies portray people with disabilities at all. But if the media are going to portray a person with a developmental disability, how about a realistic portrayal?

For example, a few years ago, a tear-jerking film called *The Other Sister* starred Juliette Lewis as a wealthy girl with a developmental disability who is extremely high-functioning and who wants to gain independence from her overprotective, though strangely uninvolved, mother. Lewis's character comes home from private, residential school and meets an extremely high-functioning boy who is taking college courses (he does need help to pass his classes). They fall in love, experience the joys of sex and eventually achieve their independence, marriage and a happy ending for all, including Mom. Sweet? Yes. Entertaining? Yes. But so is *Peter Pan*. Real? About as real as Peter's adventures in Never-Never Land.

How many people really understood the satire in *Forrest Gump*? How many just focused on Tom Hanks' sweet face, as he innocently blunders through the latter part of the twentieth century, affecting us all only for the good?

The majority of the general public base their views of people with developmental disabilities upon what they see on TV and in the movies. Perhaps they have some firsthand knowledge of the kid down the block who gets on the minivan in the morning, or the older relative who tags along with his aged parents to family functions and is "a little slow." Such realistic experiences are important because with knowledge comes acceptance, appreciation and the ability to overcome old fears and misunderstandings. If you expect to see Juliette, Sean or Tom walking with an awkward gait, you won't learn anything. But if you have the courage to open the door a little into the lives of people with developmental disabilities—by all means, swing it open all the way.

Any Saturday afternoon, come down to the bowling alley and meet my son and his friends. You won't meet Rainman, but you will meet real people grappling with autism and the social and emotional problems that come along with it. You won't meet Forrest, but you will meet young men who are graduating from school and hoping to find a job that will fulfil them. There are no girls in this group likely to have their own apartment or get married, as the "other sister" does. But there are girls—young women, really—who like boys on the team and enjoy music and dancing, and are struggling to express these feelings in an appropriate way.

> Does anyone in TV-land know that not all people with developmental disabilities look like Sean Penn, Tom Hanks or Dustin Hoffman, wearing their pants too short and dress shirts buttoned up to the neck?

You'll also meet real parents of children with developmental disabilities. The parents and their styles of parenting are varied, but there are no monsters or saints among us—though these are the two characteristics most often attributed to parents of children with disabilities in the movies. Rather, these

---

EP selects "parent editorials" for the purpose of providing a forum for emerging opinions and evolving parenting philosophies. EP also welcomes responses to previous editorials that represent divergent views. These select editorials do not necessarily reflect the opinion of EP. — Rick Rader, MD, Editor-in-Chief

Parents may send their submissions for Parent Perspective to Exceptional Parent Magazine, 65 E. Route 4, River Edge, NJ 07661; e-mail: epedit@aol.com. All submissions are subject to review and editing by EP.

"real" parents are, like all parents, worried about their children's future. But these parents are also worn down from the constant struggles with schools and with their children's social isolation. They are sometimes frustrated, sometimes even confused, depressed or angry, but they are always ready with a helping hand and a laugh. You have to have a wicked sense of humor to get through this life.

Does anyone in TV-land know that not all people with developmental disabilities look like Sean Penn, Tom Hanks or Dustin Hoffman, wearing their pants too short and dress shirts buttoned up to the neck? My son and all his friends are outright fashion plates, wearing the latest style, their favorite sports teams' logos and the hippest sneakers and hairstyles. They want to look good, and we make sure they do. God knows they stand out from the crowd enough without walking around dressed like Howdy Doody!

It's time for TV and the movies to portray real and ordinary people with developmental disabilities. Even today, when a national talk show features someone with developmental disabilities, it's a very high-functioning, attractive, pixyish person. I guess we should be grateful for any exposure at all, but I'm still waiting for a talk-show host to interview someone like my son and his friends. These young adults with mental retardation may not be so "cute" anymore. They may not have a perfect smile or they may have missed half their faces when they shaved, but they have triumphed by shaving at all!

Come on, Hollywood! Anyone want to come and make a movie about us? We've got it all: drama, suspense, triumph, tragedy and, believe it or not, lots of laughs. Is there anyone in the media courageous enough to tell the real story of your average, run-of-the-mill individuals with developmental disabilities and their families?

Show a story about real heroes: the parents who get up every morning and do all the things that you could never imagine you would still have to do for your adult child, before you were thrust into the different, parallel universe of the family with "special needs." Show us as neither saints nor sinners, but as real parents who love their children. Show our children as three-dimensional human beings, who grow up to be adults who do not look like Sean, Juliette or Tom in bad wardrobes.

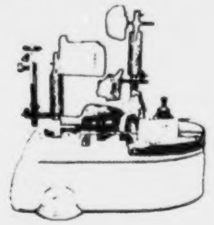
There are great love stories buried in here, Hollywood! Real love stories. Take the time and courage to find them. And hey, it's okay if Julia Roberts wants to play me. EP

Roseann Forziano is the community educator for the Epilepsy Foundation of Long Island and a columnist for a local newspaper. Her 18-year-old son, Paul, has developmental disabilities.

Early Childhood Mobility

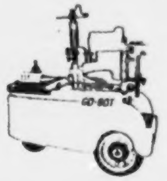
Mini Go-Bot's

Century Stander

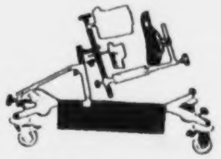


Stanford Standard

Note: Standing frames work with either Go-Bot



Yellow Go-Bot



GB-I Gait Trainer
(can be customized)

Innovative Products, Inc.

1-800-950-5185

Web Site: www.iphope.com

Circle #51 or visit www.eparent.com/adinfo

Special Care for Special People

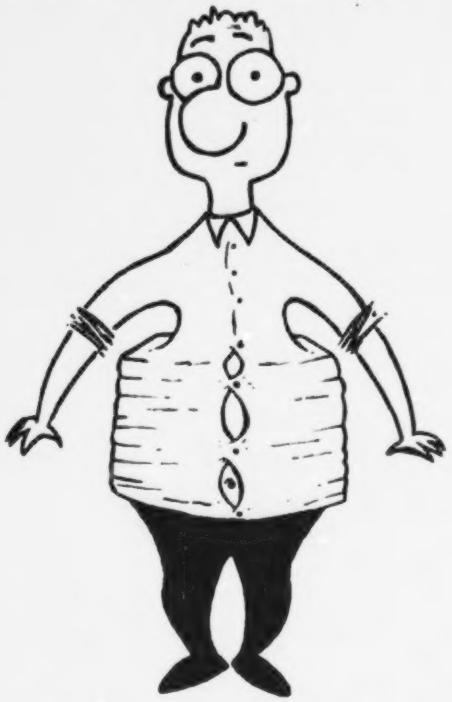
Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #71 or visit www.eparent.com/adinfo

As our volunteer clearly demonstrates, 21* pediatric medical journals can be quite difficult to digest.



In fact, unless you have a medical degree we wouldn't recommend it.

If you have an interest in the latest breakthroughs and research published in pediatric journals, but don't have the medical training required to easily digest the information, there is an alternative.

ChildHealthMonitor.org publishes articles adapted from the latest monthly issue of each of the world's leading pediatric publications*. The information is the same. The difference is that much of the medical jargon is replaced with everyday language. It's also online which means that anyone with an Internet connection can now have instant access to reliable, useful information on the latest advances in treatment, prevention, and caring for kids.

Simply, visit **www.childhealthmonitor.org** and you too can have unlimited access to hundreds of simply written articles on up-to-the-minute pediatric discoveries.

We think you'll find this option much more palatable. (Our volunteer did.)

* Acta Paediatrica, Archives of Disease in Childhood, Archives of Pediatrics and Adolescent Medicine, Brain and Development, British Medical Journal, Child: Health, Care and Development, Developmental Medicine and Child Neurology, European Journal of Pediatrics, Journal of Adolescent Health, Journal of Child Psychology and Psychiatry, Journal of Paediatrics and Child Health, Journal of Pediatric Psychology, Journal of Pediatric Surgery, Journal of Pediatrics, Journal of the American Academy of Child and Adolescent Psychiatry, Journal of the American Medical Association, The Lancet, New England Journal of Medicine, Pediatric Infectious Diseases Journal, Pediatrics, and Research in Developmental Disabilities.

CHM

ChildHealthMonitor.org

organizational spotlight

National Disability Sports Alliance

Sports For All

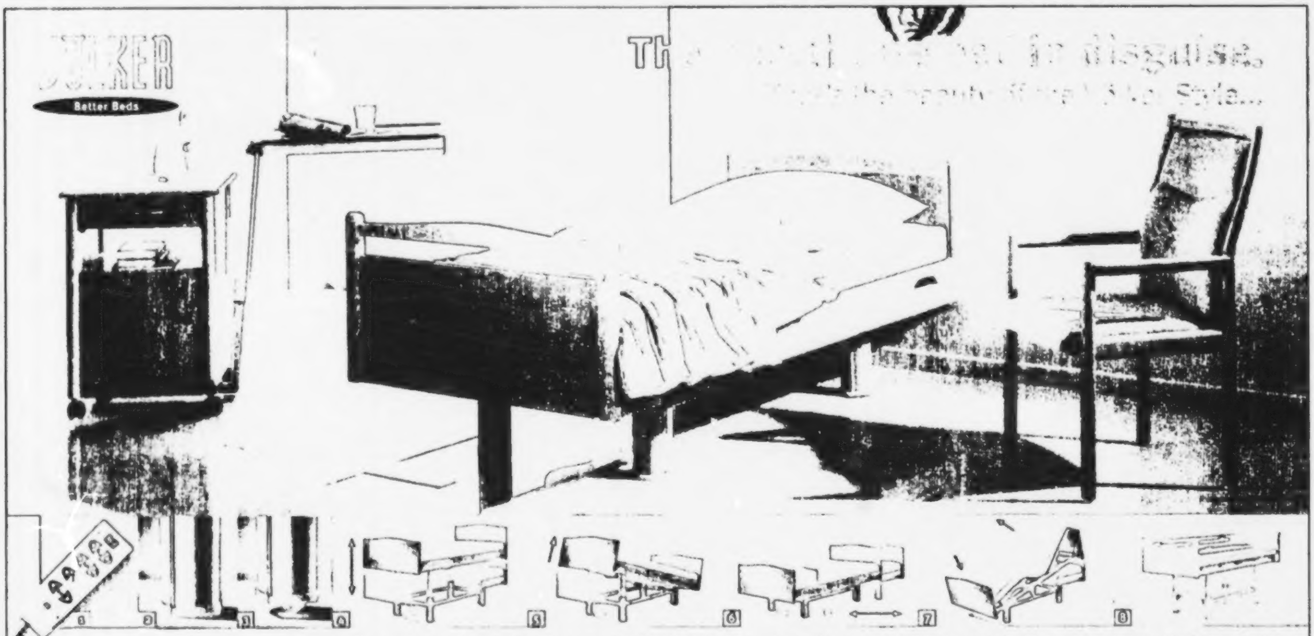
For more than 25 years, the National Disability Sports Alliance (NDSA) has been providing individuals with physical disabilities opportunities to participate in competitive sports, as well as recreation and fitness activities. Historically, the NDSA's primary focus has been on serving individuals with cerebral palsy and survivors of brain injury and stroke. Originally incorporated as the United States Cerebral Palsy Athletic Association, the name was changed in 2001 to reflect the growing number of disability groups represented. The new name also reflects NDSA's mission of providing a national structure for competitive sports among those with a wide range of physically disabling conditions, including muscular dystrophy and multiple sclerosis. Several sports are open to anyone with a diagnosed physical disability.

The organization's motto, "Sports For All," is promoted through numerous programs that allow an athlete, regardless of functional ability, to train and engage in highly competitive sports. To this end, NDSA has established a multilevel competitive system for both wheelchair users and individuals who are ambulatory. Once an appropriate level is determined, the athlete may choose from individual sports—competing against others at the same level—and team sports. This assures the most equitable form of competition. NDSA also has a strong competitive program for youth that uses age groupings in the following sports: bocce, bowling, cycling, equestrian, indoor wheelchair soccer, swimming, soccer and track and field.

The competitive events offered through NDSA have been organized with careful criteria to maximize the true sports nature of the competitions involving individuals with physical disabilities. NDSA holds clinics throughout the US where individuals who wish to serve as competition officials must demonstrate their abilities.

Along with six other national disability sports organizations, NDSA is a Community Based Organization (CBO) member of the United States Olympic Committee, joins such national groups as the YMCA, Jewish Community Centers, the Boys and Girls Club and similar orga-

continued on page 101



1. Electric operation via a hand control or nurse console (optional). **2.** Absolutely secure braking. **3.** Electric push button casters. **4.** Stable height adjustment 15 1/2–31 1/2" (13 3/4–27 1/2" optional). **5.** Trendelenburg/reverse Trendelenburg (optional). **6.** Easy to move on disappearing casters. **7.** Tilt-in-space positioning that allows for sitting (cardiac) or reclining chair. **8.** Disappearing full lenght side rails.

For more information call 1-800-321-4240

Hertz Supply Co., Inc. · 4670 Schantz Rd., Suite A · Allentown, PA 18104 · www.hertzsupply.com

Hertz SUPPLY

Circle #47 or visit www.eparent.com/adinfo

623

Getting information from EP advertisers is MUCH FASTER ONLINE!

It's as easy as a click of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in EXCEPTIONAL PARENT.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.

Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
22	ADAPTIVEMALL.COM	20
17	ANDERSON SCHOOL	110
18	ANNANDALE VILLAGE	8
19	ANNE CARLSEN SCHOOL	73
21	ASSOCIATION OF DRIVER EDUCATOR	115
24	BODYPOINT DESIGNS, INC	22
23	BODYPOINT DESIGNS, INC	65
25	CAMPHILL SPECIAL SCHOOL	81
26	CHILDREN'S HOSPITAL	4
27	COLUMBIA MEDICAL	21
28	CONNETQUOT WEST	115
29	COTTING SCHOOL	81
30	CROTCHED MOUNTAIN REHAB	77
31	CRYSTAL SPRINGS SCHOOL	90
32	CYBERONICS, INC	12
	CYCLETOTE CORP	34
33	DRIVE MASTERS	20
34	DYNAVOX SYSTEMS LLC	69
35	EDEN FOODS, INC	33
200	EP LIBRARY PAGES	104-105
49	EP NEWBORN SCREENING DVD	36
199	EP SUBSCRIPTION CARD	17
36	EQUIPMENT SHOP	90
37	EVERGREEN CENTER	66
	FAMILY CAFÉ	88
38	FORD MOBILITY	C3
39	FRANK MOBILITY	76
40	FREEDOM CONCEPTS	111
41	FREEDOM DESIGN	63
42	FREEDOM MOTORS USA	85
	GENERAL MOTORS	87
43	GLOBAL POWER SYSTEMS INC	67
44	H.D.I.S.	39
45	HARD MANUFACTURING	16
46	HAVERICH ORTHO-SPORT, INC	68
20	HEARSPRING	35
47	HERTZ SUPPLY CO., INC	97

CIRCLE#	ADVERTISER	PAGE#
48	HMS SCHOOL	66
	HOUSE AD	98
50	HOUSE AD	56
51	INNOVATIVE PRODUCTS	95
52	ISLAND DOLPHIN CARE	23
53	KENNEDY KRIEGER	61
54	KIMBERLY CLARK CORP	31
55	LAWYERS, INC	57
56	LIBERTY MOTOR COMPANY INC	83
57	LITIGATORS, INC	93
59	MEDTRONIC NEUROLOGICALS, INC	C2
60	MELMARK	19
61	MOBILITY RESEARCH	38
	NAT'L DISABILITY SPORTS ALLIANCE	64
62	NMEDA	109
63	OCEAN HYPERBARIC CENTER	89
64	PFIZER, INC	7
65	PRECISION FOODS	75
66	RED BARN ENTERPRISES	39
67	SIGMA TAU	1-2
68	SNUG SEAT INC	25
69	SOUTH FLORIDA CNTR FOR HOPE	24
70	SOUTHPAW ENTERPRISES, INC.	67
71	STEWART HOME SCHOOL	95
72	THE BABY JOGGER COMPANY	24
73	THE CENTER FOR DISCOVERY	9
74	THERADAPT	62
75	TORONTO HYPERBARIC INC	79
76	VAIL PRODUCTS	C4
	VANTAGE MOBILITY	84
77	VERIZON	3
78	WHEELCHAIR GETAWAYS	76
79	WOODBURY PRODUCTS	23
80	WORLD CONGRESS	40-43

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms,
300 North Zeeb Road, Ann Arbor, MI 48106

continued from page 97

nizations to form the CBO Council.

Since 1978, athletes from NDSA have represented the US in such international competitions as the 1984 International Games for the Disabled and the '88, '92, '96, and 2000 Summer Paralympic Games. NDSA athletes hold numerous world records in cycling, swimming and track and field. NDSA will host the 2005 World Games for Athletes with Cerebral Palsy, a major international event that will bring more than one thousand athletes from 60 countries to the United States.

The NDSA board of directors has begun an aggressive national marketing campaign to reach out to any and all individuals who could benefit from participation in sports, recreation and fitness activities and increase athletic membership, especially among youth. The NDSA firmly believes in the importance of youngsters with disabilities capitalizing on their abilities and potential athletic success.

In 2001, the US Olympic Committee created a new division, the US Paralympics, to manage elite paralympic sport in the US. NDSA has now refocused its efforts to grassroots and youth programs and is even more committed to reaching out to the hundreds of thousands of American youth with physical disabilities who could benefit from participation. Plans are under way to create affiliate programs throughout the country.

NDSA sanctions numerous local and regional events which lead to participation at the national level. The organization's "showcase" annual event is the National Sports Festival For The Disabled. This event serves as the national championships in seven of NDSA's sports. In 2000 the event also hosted the selection trials for the US Paralympic Track and Field Team. The 2002 event will include the Junior Nationals for Wheelchair Sports USA, as well as NDSA's junior and adult championships. The Festival will take place June 24-July 1 in New London, Connecticut. (See *What's Happening* for more details.)

After a quarter of a century, the National Disability Sports Alliance is still working to ensure that there will always be "Sports For All." EP

For more information, contact:
National Disability Sports Alliance
25 West Independence Way
Kingston, RI 02881
(401) 792-7130
E-mail: info@ndsaonline.org
Web site:
http://www.ndsaonline.org

Editor's Note: EP is pleased to announce that the NDSA will begin contributing an occasional column on sports, recreation and fitness for people with disabilities.

Customized Smiles

Everyone is different. Different shapes. Different sizes. Different needs. That's why at Danmar we customize our products for each individual. Seating and positioning devices which fit to a T. Helmets custom-designed for pony tails or buzz cuts. Swim aides so secure you're a fish in the water. You have a special need. We have a special product, one custom made for your smile.

Website: www.danmarproducts.com
Phone: (800) 783-1998

DANMAR

Special Products for special needs since 1968.

Danmar Products, Inc., 221 Jackson Industrial Drive, Ann Arbor, MI 48103 USA

Circle #28 or visit www.eparent.com/adinfo

625

PART XI

Orthodontic Care for The Person With Special Needs:

AN OVERVIEW

By Michael B. Koidin, DDS, MScD

At first consideration, orthodontic care for the child or adolescent with special needs may appear to be superfluous in light of all the other parameters governing such an individual's daily existence. After all, daily lifestyle maintenance issues such as feeding, dressing and mobility should take precedence over the seemingly superficial importance of having "straight teeth." However, if one looks beyond the vanity factor fostered by our society's valuation of the beautiful smile, the importance of overall orthodontic health for the special needs population becomes apparent.

The incidence of malocclusion (unaligned or "bad" bite) in people with developmental disabilities is markedly higher than in the rest of the population, as has been shown in several studies done in Europe and the United States. This increased frequency of orthodontic problems is certainly multifactorial, ranging from inherent growth and development anomalies common to many syndromes, such as cross-bites in people with Down syndrome, to malocclusions. These may develop as a result of dental neglect and lack of professional supervision; for example, premature loss of primary (baby) teeth can lead to drifting and crowding of permanent teeth. Therefore, an orthodontic examination and assessment should be considered an integral aspect of dental care for every person with special needs.

Early orthodontic care, often termed preventive or interceptive treatment, is generally intended to avoid and/or minimize potentially harmful patterns. Such an approach of early intervention is particularly important for a person with a developmental disability who may not be able to tolerate braces or similar traditional orthodontic treatment. An important aspect of preventive orthodontics includes good restorative care of both primary and permanent teeth since space loss, crowding and even tooth impaction can result from dental decay and its consequences.

Another aspect of interceptive orthodontics is the timely removal of primary teeth so that they do not block or deflect the underlying permanent teeth from their proper eruptive paths. When these baby teeth are over-retained—when they are not shed on schedule—the result can be harmful cross-bite positions or impactions, which can become difficult orthodontic therapeutic challenges in a person with special needs.

Correction of functional asymmetries by early treatment intervention is also important to the orthodontic health of people with special needs. The promotion of symmetrical jaw growth in the young child is often essential in minimizing future orthodontic problems. Treatment may range from selected extractions of either primary or permanent teeth to rather complex orthodontic/orthopedic appliances designed to stimulate and/or favorably redirect bone growth. In many cases, especially with people exhibiting dentofacial anomalies (see the December 2001 and February 2002 issues of EXCEPTIONAL PARENT for descriptions), a team approach is used, with disciplines ranging from plastic surgery to oral surgery to orthodontics involved in the overall treatment. Therapy may be staged over many years; for example, corrective treatment for people with cleft lip/cleft palate may begin shortly after birth and can often continue into early adulthood.

As a dual-trained pediatric dentist and orthodontist, it has been my basic philosophy to offer all aspects of treatment—from preventive to restorative to orthodontic treatment—to everyone I see in my practice. It is our office's goal to provide every person with optimal dental health, functionally and cosmetically, irrespective of any disability. However, this philosophical idealism must be tempered with certain realities, as I have learned over the past twenty-four years. Nowhere else do these realities make themselves more apparent than in the orthodontic realm.

The decision to initiate orthodontic therapy on a person with special needs is based on the same parameters as it would be for any other person. Severity of the malocclusion, tooth eruption patterns, oral hygiene level, periodontal (gum tissue) status, decay activity and functional and esthetic issues are all considered before beginning active treatment. The issues of cooperation and risk/benefit, however, may take precedence in the decision-making process.

People with mild to moderate disabilities may often prove to be quite cooperative and compliant with the requirements of fixed orthodontic appliance therapy. Parental assistance with some aspects of treatment, such as headgear wear, expansion appliance adjustments and elastic wear, can be of great benefit in creating a successful therapeutic outcome. Of prime importance is the need to educate parents and direct support professionals (DSPs) about the necessity of maintaining good oral hygiene throughout the orthodontic process and how to accomplish that goal. This increased awareness about dental issues helps to avoid periodontal flare-ups and decay activity, which could interfere with treatment. Making parents and DSPs active participants in the therapy regimen provides another line of defense against the pitfalls of cooperation that seem to plague every orthodontic practice. Ironically, a good attitude on the part of parents and DSPs can make orthodontic treatment easier for a person with special needs than comparable therapy for a child without any special needs.

Practical considerations of cooperation, oral hygiene levels and safety must all be evaluated and explained to the parents and DSPs, who often have unrealistic expectations of what can be accomplished.

More severe disabilities, whether emotional, mental or physical, may preclude the use of traditional fixed orthodontic appliances. Practical considerations of cooperation, oral hygiene levels and safety must all be evaluated and explained to the parents and DSPs, who often have unrealistic expectations of what can be accomplished. Other treatment plans—whether in the form of an abbreviated, simplified course of therapy, or in the timely removal of primary or permanent teeth in order to alleviate crowding—may need to be presented and discussed. Risk/benefit is the concept that should be kept in the forefront when considering orthodontics for people with more severe special needs. Regardless, every person with developmental disabilities should be considered individually and given care, if at all possible. With patience and understanding, surprising and gratifying treatment victories may be achieved!

When all is said and done, orthodontic treatment is an elective procedure in the majority of cases, regardless of its functional and esthetic benefits. As applied to the population of people with special needs, orthodontics may be considered super-elective, especially for people with more severe disabilities. The overall needs of each individual person should be evaluated. If approached in this light, orthodontic therapy for the person with special needs can be highly rewarding for the orthodontist, parents, family members, DSPs and the person receiving the therapy.

Michael B. Koidin, DDS, MScD, is Assistant Clinical Professor of Pediatric Dentistry at The Boston University School of Dental Medicine. Dr. Koidin is trained in both pediatric dentistry and orthodontics and is in private practice in Lynn, MA.

WWW.EPLIBRARY.COM

EP Exceptional Parent LIBRARY

THE SPECIAL NEEDS BOOKSTORE

PARENTING

THE ANGRY CHILD
Regaining Control When Your Child is Out of Control
TIM MURPHY, PH.D.

Anger can be a normal response to frustration or disappointment, but for some children it is an ingrained behavior that caused them and those around them needless misery. This book provides both the roots and the solutions for uncontrollable anger in children. Learn the 10 characteristics of the angry child; Four stages of anger and how to cope; the 5 C's of successful parenting and much more.

RW676XPA $24.00

FATHER NEED NEW!
Why Father Care Is as Essential as Mother Care for Your Child
KYLE D. PRUETT, M.D.

An easy to follow handbook which offers in depth advice for parenting children of all age groups from infancy through adolescence and adulthood. Learn not only why a father needs to take an active role in raising children, but also how to do so effectively.

RH237XPA 13.95

SPECIAL KIDS NEED SPECIAL PARENTS
A Resource for Parents of Children with Special Needs
JUDITH LOSEFF LAVIN NEW!

Parents of children with special needs face unique emotional and practical challenges every day. These issues are seldom fully addressed by the medical community—an parents' most compelling questions remain unanswered. The author draws upon interviews with health care professionals, nationally recognized authorities and families of special need children to give readers the advice, encouragement and comfort they crave.

GP6622PA $13.95

THE PARENT TO PARENT HANDBOOK
Connecting Families of Children with Special Needs
BETSY SANTELLI, FLORENE STEWARD POYADUE, JANE LEORA YOUNG

As a parent you have lots of questions. If you child has a disability you probably have even more. One of the best ways to find answers to your questions is through "Parent to Parent Programs". Written by two mothers that have been there this book will explain how these valuable programs work and how they can give you the help you need.

PB4979GN $29.95

ASPERGER SYNDROME

BLUE BOTTLE MYSTERY
KATHY HOOPMANN

A warm, funfilled fantasy story that enables children with Asperger syndrome to read about their disability in a non threatening way that promotes the best in them.

TF9785 NEW! $11.95

ASPERGER SYNDROME, THE UNIVERSE, AND EVERYTHING
KENNETH HALL

The author was diagnosed with Asperger Syndrome at age eight, and now he describes some of the inner experiences and perceptions a child with autism has from a unique perspective that only one who has been through it can truly explain.

TF9300AS $11.95

OF MICE AND ALIENS
An Asperger Adventure
KATHY HOOPMANN

Ben, recently diagnosed with Asperger Syndrome, and his friend Andy uncover an alien spaceship that crash landed in their backyard. With Ben trying to cope with his disorder, and the alien trying to cope with life on earth, adventure ensues.

TF007XAS $11.95

FOR YOUNG PEOPLE

BEN KING OF THE RIVER
DAVID GIFALDI WITH ILLUSTRATIONS BY LAYNE JOHNSON

The touching story of Ben, a young child with a developmental disability, and his brother who encounter some different and exciting situations and people on a family camping trip.

AW6354YP $14.95

BABY ON THE WAY
WILLIAM SEARS, MD, MARTHA SEARS, RN, AND CHRISTIE WATTS KELLY WITH ILLUSTRATIONS BY RENEE ANDRIANI

When a family is expecting a new baby there are many changes that take place. This warm insightful book helps children and their parents joyously and lovingly prepare for the newest member of the family.

TW767YP NEW! $12.95

WHAT BABY NEEDS
WILLIAM SEARS, MD, MARTHA SEARS, RN, AND CHRISTIE WATTS KELLY WITH ILLUSTRATIONS BY RENEE ANDRIANI

When a family brings a new baby home there are many changes. This children's book clearly explains baby's needs while emphasizing how siblings can be helpers to both baby and parents, while forging their own relationships with "the baby".

TW8287YP NEW! $12.95

EPILEPSY

THE KETONGENIC DIET
A Treatment for Epilepsy
JOHN M. FREEMAN, MD, JENNIFER B. FREEMAN, MILLICENT T. KELLY, RD, LD

Devoted exclusively to explaining a unique doctor approved approach to minimizing seizures, this book is a must have for all families affected by epilepsy and seizures. The diet presented within is high in fat and low in carbohydrates and protein, helping to control seizures and allow children to lead normal seizure and drug free lives.

DE9390EP $24.95

YOUR CHILD AND EPILEPSY
Robert J. Gumnit, M.D.

This book is designed to help both patients and healthcare professionals to understand all aspects of diagnosis, and of pharmacological and surgical management. It will help parents and older children with epilepsy to participate more knowledgeably with their health care providers.

DE7760EP $24.95

SEIZURES AND EPILEPSY IN CHILDHOOD
A Guide for Parents
JOHN M. FREEMAN, M.D.

This Second Edition in addition to providing up to date information about new diagnostic techniques, drugs, diet and surgical treatments; includes a new chapter addressing the special needs children with epilepsy have regarding routine health care.

JH4989EP $17.95

HEALTHCARE

ASK A NURSE
From Home Remedies to Hospital Care
AMERICAN ASSOCIATION OF COLLEGES OF NURSING
EDITED BY: GERALDINE BEDNASH, PH.D., R.N., FAAN

This book provides comprehensive information on standard treatments, home remedies, and effective over-the-counter medications for health problems ranging from allergies to yeast infections. With the expertise of 550 nursing schools and personal advice from 100 registered nurses nationwide, you can learn what to do whey your or a family member is sick and in need of care. Chapters are arranged alphabetically so it is easy to find what you need.

SS6875CN $30.00

TRANSCULTURAL ASPECTS OF PERINATAL HEALTH CARE
A Resource Guide
NATIONAL PERINATAL ASSOCIATION

This book, revised in March 2002, offers resources and information supporting requirements of the Office of Civil Rights, the Maternal and Child Health Bureau of HRSA, and JCAHO in Cultural Sensitivity, Cultural Competency, Core Health Status Indicators, Developmental Health Status Indicators, Interpreter Competency and Patient Education. A great source for Title V Applications. User Friendly chapters, fourteen (14) so far, include narrative and support sections. Easy to include updates as they become available.

EP8020PN $79.00
EP8021PN (March, 2002 Update) $19.95

PHYSICAL DISABILITY

TORTICOLLIS
Differential Diagnosis, Assessment and Treatment, Surgical Management and Bracing
KAREN KARMEL-ROSS, PT, PCS, LMT

Clearly reflects the philosophy of the team approach by including contributions from a pediatric orthopedist, pediatric general surgeons and several pediatric physical therapists. Reviews the differential diagnosis and surgical management of CMT and provides a detailed, comprehensive approach to the nonoperative management of CMT by bringing together a wide range of related materials under one cover.

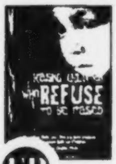
HP3171OS $24.95

EP LIBRARY • (800) 535-1910 • EPLIBRARY@AOL.COM

Easy for You to Say
Miriam Kaufman, MD
Q & As for Teens Living With Chronic Illness or Disability
This book addresses issues faced by teens and young adults with disabilities and chronic conditions. The information is presented in a straightforward questions and answer format that can easily be browsed through, rather than read cover to cover. Divided into eight chapters to enable the reader to jump to a topic of interest such as Doctors and Medical Issues; Friends and Dating or Sexuality plus much more.
KP6194CI **$15.95**

BEHAVIOR

The Anti-Bullying Handbook
Keith Sullivan
Written for Parents, teachers, administrators, counselors, therapists this resource can help us to understand what bullying is and how to arrest it or to prevent it. Part I gives a clear overview of what we understand about bullying and Part II provides information on how to deal with with bullying.
OU3884BE **$19.95**



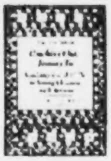
Raising Children Who Refuse to Be Raised
Dave Ziegler, Ph.D.
This book is for both parents and professionals who are involved with the care of children who have severe emotional or behavioral disturbances as the result of abuse or neglect. The three major sections cover: Emotional disturbances, Where it all Begins; Behavioral Disturbances: There is More than Meets the Eye; and lastly Advanced parenting Skills and Challenges. The 12 chapters contain detailed discussions of emotional or behavioral disorders, their causes and possibilities for treatment.
AC8727BH **$19.99**

AUTISM

Through The Eyes Of Aliens
A Book About Autistic People
Jasmine Lee O'Neil
This is a rich and positive description of how it feels to be autistic and how friends, family and the professionals that work with autistic people can be more sensitive to their needs. Written with a creative spin by an author who is autistic herself.
TF009AT **$24.95**

Exiting Nirvana
A Daughter's Life with Autism
Clara Claiborne Park
The sequel to "The Siege", this book finds Jessy Park, now an adult, still struggling with language, with hypersensitivity's and obsessions, and with the social interactions that ordinary people take for granted but she cannot understand. With the help of family, teachers, and friends, Jessy has achieved more than her parents could have hoped for. This is a moving story about the making of a self and what it means to be human and a contributing active member of her family and community.
LB1176AT **$23.95**

Son Rise
The Miracle Continues
Barry Neil Kaufman
An inspiring journal of a family's successful effort to reach their autistic child. Includes stories of other. families who have used the same approach to heal their special children.
OI039AM **$20.00**



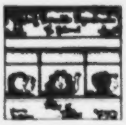
Reaching Out, Joining In
Teaching Social Skills to Young Children with Autism
Mary Jane Weiss, Ph.D., BCBA & Sandra L. Harris Ph.D.
Designed to show parents and professionals how to help young children with Autism with one of their most challenging areas of development—Social behavior this book covers four broad topics. This book focuses on the following areas: play skills; the language of social skills; understanding another person's perspective; and using these skills in an inclusive classroom. This guide offers invaluable expertise and easy to understand activities parents and teachers can practice at home or at school to help kids with autism in preschool through elementary schools become more socially adept.
WB7240AT **$16.95**

Autism Through the Lifespan
The Eden Model
David L. Holmes, Ed.D.
A unique and detailed look at a successful approach to treating and caring for children with autism. Parents, teachers, and treatment professionals will find this book to be informative and insightful reading.
WB176AT **$21.95**

TOURETTE SYNDROME

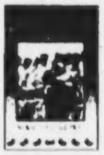
Tourette Syndrome: Finding Answers and Getting Help
Mitzie Waltz
NEW!
Tourette's syndrome is a neurological disorder usually diagnosed in childhood. It is characterized by tics, physical jerks and involuntary vocalizations. Some people with Tourette's also have other brain-based disorders, particularly ADHD or OCD. This book is designed to help you: Secure accurate and complete diagnosis; Live with Tourette's in the family; Understand medical interventions; Obtain appropriate medical care from an existing health plan; Find resources and much more.
OA0076TS **$24.95**

Children With Tourette Syndrome
A Parents' Guide
Edited by T. Haerle
Written by a team of professionals and parents, this book covers medical, educational, legal, family life, daily care, and emotional issues.
WB01600 **$14.95**

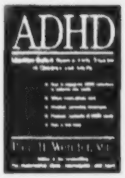


Taking Tourette Syndrome to School
NEW!
Tira Krueger with illustrations by Tom Dineen
This excellent children's story about a girl with Tourette Syndrome is essential for any family that wishes to understand what the disorder is, where it comes from, and what impact it has on the child's life.
JB3124TS **$11.95**

ATTENTION DEFICIT



Distant Drums, Different Drummers
A guide for young people with ADHD
Barbara D. Ingersoll, Ph. D.
A view that offers children and adolescents struggling with ADHD the opportunity to see themselves in a positive light due to their penchant for novelty and exploration and boundless energy.
CP100AD **$15.95**



ADHD
Attention Deficit Hyperactivity Disorder in Children, Adolescents, and Adults
Paul H. Wender, M.D.
This book is filled with extensive case histories of children and adolescents with ADHD. It contains valuable information on where to seek help, as well as on the kinds of diagnostic tests currently available. This is a must have for parents of children with ADHD.
OU3497AD **$10.95**

Teaching Teens with ADD and ADHD
A Quick Reference Guide for Teachers and Parents
Chris A. Zeigler Dendy, M.S.
Recognizing the pivotal role teachers play in the long term success of their students, this book provides information via 75 concise summaries on key issues related to attention deficit disorder. Beyond the thorough review of the basics, this guide also illustrates how the characteristics of the disorder can affect academic performance while presenting strategies interventions and tips to make teacher's jobs easier.
WB7208AD **$18.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: **EP**, Dept. EP0502, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call **800•535•1910**

QTY.	ITEM#	UNIT PRICE	TOTAL
		Sub-Total	
		NJ Residents 6% Sales Tax	
		Shipping	
		TOTAL	

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

These prices are subject to change without notice.

Name ____________________

Address ____________________

City ____________________ State ________ Zip ________

Telephone ____________________ E-Mail ____________________

I have enclosed my check payable to Exceptional Parent or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover

Account Number: ____ ____ - ____ - ____ Exp. Date ____ /____

Signature ____________________

Circle #200

TRANSITIONING

Gynecological and Reproductive Healthcare for Women with Special Needs

By Catharine A. Kopac, PhD, GNP

Over the past decade I have collaborated with Joni Fritz, former director of the American Network of Community Options and Resources (ANCOR), in researching the gynecological and reproductive healthcare of adolescent and adult women with developmental disabilities. My own education as a gerontological nurse practitioner, coupled with Joni's experience in the field, has enabled me to begin to build a bridge of understanding to the challenges that adolescents and women with special needs encounter when seeking healthcare. I rely on Joni's insight as I struggle to interpret the data and reach conclusions. Our early work demonstrated that frequently, a central figure in the provision of gynecological and reproductive (gyn/rep) care for adolescent and adult women with special needs is the professional nurse. In addition, the early work raised many questions and left us unsatisfied with the quality and bias of our data. Consequently, we decided to query nurses who work in the field of women's health about their perceptions of the adequacy of gyn/rep care for women with developmental disabilities. This article will review some of the central findings of a survey of 727 professional nurses—representing four professional nursing organizations—from across the United States.

Introduction and Historical Perspective

Over the past several decades, care for persons with developmental disabilities has moved from the institutional setting to the community; at present most of these people live in community settings. As a result, the need for community-based healthcare services that target persons with developmental disabilities has been recognized and new roles have emerged. As changes have occurred in the overall healthcare system, persons with developmental disabilities have had to adapt to managed care; considered a challenge for the average consumer, working with managed care entities may often exceed the capabilities of a person with special needs. Despite the Americans with Disabilities Act of 1990, the present healthcare system often fails to accommodate the needs of persons with developmental disabilities because healthcare professionals are poorly educated and poorly prepared to offer services for persons with special needs. Additionally, the scope of the need for gynecological and reproductive care for adolescent and adult women with special needs remains outside the purview of the average healthcare administrator. While acknowledging that the person with a disability cannot be discriminated against, the administrator knows that the number of persons with special needs who seek care is small and therefore not a priority. And finally, there is an underlying perception about the basic needs of persons with cognitive challenges. Sulpizi reported that "the reproductive needs of women with developmental disabilities are often overlooked in the delivery of healthcare because these women are regarded as somehow asexual."

In what is perhaps the only reported long-term study of healthcare utilization for people with developmental disabilities, Rowitz and Farber described a 25-year follow-up study of families with a member who is severely handicapped. They found that the most frequently used healthcare professionals were general practitioners, pediatricians, dentists and neurologists, while those most infrequently used included gynecologists, cardiologists, orthodontists, oral surgeons, plastic surgeons and chiropractors. Thus, there clearly is a need to study the gynecological and reproductive care available to adolescent and adult women with developmental disabilities.

The Survey

The purpose of the survey was to examine the accessibility and availability of gynecological and reproductive services from the perspective of professional nurses. A questionnaire was mailed to 3451 potential respondents who were members of four different professional nursing organizations:

- American College of Nurse Midwives (a random selection of 14.2 percent of the membership)
- Association of Women's Health, Obstetric and Neonatal Nurses (a random selection of 27.1 percent of the membership who list their specialty as women's health)
- American Association on Mental Retardation (entire membership of the Nursing Division)
- Developmental Disabilities Nurses Association (entire membership)

The 727 nurses responding to the mailing had an average age of 46.3 years. Nearly half had a master's degree or higher. Although highly educated, a large percentage of the respondents (634 = 88.5 percent) reported that their basic nursing education did not include curricula on clinical approaches and treatment of adolescent and adult women with developmental disabilities. Moreover, almost 70 percent reported that they had no continuing education about developmental disabilities. These numbers

* This article is based on a study that was funded in part by Tau Chapter, Sigma Theta Tau International and the American Network of Community Options and Resources (ANCOR).

are alarming—nurses are not receiving basic education in the care of persons with special needs. Nor are a large number of them taking advantage, or even aware, of educational opportunities offered by the Developmental Disabilities Nurses Association (DDNA) or the American Association on Mental Retardation (AAMR), Nursing Division. This is particularly troubling because more than half of the nurses in the sample further reported that there was no one in their clinical setting with special training in working with adolescent or adult women with special needs.

Table One

The Availability of STD/HIV Services

Rated by Professional Nurses

TYPE OF SERVICE	RATING OF SERVICE [NO. (%)]			
	All/Many*	Some*	None	N/A**
STD Screening	229 (45.0)	137 (26.9)	117 (23.0)	25 (4.9)
Counseling/Rx STD	194 (38.9)	117 (23.3)	163 (31.9)	27 (5.3)
HIV Testing	163 (32.3)	103 (20.4)	208 (41.2)	30 (5.9)
Counseling/Rx HIV	166 (32.8)	103 (20.4)	208 (41.2)	30 (5.9)

*The category of "All/Many" is a combination of separate categories of "All" and "Many"; the category of "Some" is a combination of separate categories of "Some" and "Few." The combinations were made to provide for the interpretation of the data.

**The category of N/A (Not Applicable) enabled the respondents to identify if the particular service being rated was not applicable to their respective clinical setting.

There were 727 completed surveys in the study; for the listed services, not all respondents rated every service, consequently the horizontal totals do not equal 727.

STD=sexually transmitted disease; HIV=human immunodeficiency virus; Rx=treatment

Services Provided

Only 48.1 percent of the responding nurses reported that health education was available to "all or many" of the women in their clinical settings. This indicates that the majority of clinical agencies these nurses represent do not routinely provide health education to this population. With its major care focus on empowerment of people to become more independent and to assume responsibility for caring for themselves, that nurses find this aspect of healthcare delivery so lacking is difficult to believe. In a previously reported study, Kopac and colleagues found that women with developmental disabilities were expressing the desire to have more health education.

Another surprising finding was that so many of the clinical agencies for which the respondents worked did not provide counseling and/or treatments for STDs or HIV infections, and many clinical settings did not even provide STD screening and HIV testing (see Table One). The low level of STD-related services raises concern because AIDS is now spreading among people with developmental disabilities. Unfortunately, many professionals have the mistaken belief that people with disabilities are asexual. When the assumption of asexuality is coupled with the challenge of providing healthcare education on STDs to people with developmental disabilities and cognitive challenges, the results are often less than satisfactory. The low level of STD services and the apparently low use of health education services lead one to believe that protection against the spread of HIV infections and other STDs may be alarmingly inadequate.

Barriers to Care

The majority of the nurses (81.4 percent) reported that they encountered barriers to providing adequate care. The two cited most frequently were a lack of empathy and/or knowledge on the part of the healthcare provider, and difficulty finding primary care providers who were willing to care for women with developmental disabilities. This finding supports the need to promote education of healthcare professionals in the provision of gynecological and reproductive services to adolescent and adult women with developmental disabilities. Difficulty finding providers may also be related to financial concerns, because many providers choose not to treat persons insured through Medicare or Medicaid. Fifty-eight of the nurses reported that insurance would not cover the service required or the time needed to do an exam or other procedures.

These barriers are further compounded by the women's fear of examinations, and by communication difficulties between the women and their providers. The women's fear caused concern for a number of the nurses because it also related to the adolescent or adult woman's ability to give consent. Other listed barriers included assumptions that the woman is not sexually active, inaccessible offices or inappropriate equipment and provider fear or impatience. These barriers could largely be forestalled through education of healthcare professionals. For those professionals already in practice, continuing education programs and internships are needed.

Physical and Sexual Abuse

More than 45 percent of the responding nurses reported that they had identified physical abuse of women with developmental disabilities. In a related item, nearly half the responding nurses reported that they had identified cases of sexual abuse, while an almost equal number of nurses (335 = 46.0 percent) did not respond to the request for the type of assistance that they give these women (see Table Two). It is troubling that nearly half of the 727 responding nurses chose not to answer the questions on abuse, since nurses have such strong advocacy roles in both clinical and community healthcare settings. Sexual abuse is suspected to be underreported in persons with developmental disabilities. In an earlier study, Kopac and colleagues found that a number of agencies that serve women with developmental disabilities do not recognize the need to identify and intervene with women who

continued on page 108

continued from page 107

have experienced sexual abuse.

Table Two

Type of Assistance Given to Adolescent and Adult Women

WHO HAVE EXPERIENCED SEXUAL ABUSE	
No Response	335 (46.0%)
Referral for Counseling	79 (10.8%)
Referral to Agencies	69 (9.4%)
Provide support, careful teaching & education	49 (6.7%)
Counsel re: safety, reporting & use of shelters	48 (6.6%)
Counsel, test & prescribe for STDs	45 (6.1%)
Referral to social services	38 (5.2%)
No incidents, not necessary, too old	36 (4.9%)

Ethical Concerns

The response of the nurses to a question on ethical concerns reflected the strong advocacy role that nurses play. When listing their concerns, they first and foremost identified inadequate services, which they saw as being related to a lack of funding for these services (see Table Three). This was followed by a number of issues related to sexuality and contraception and multiple issues involving informed consent. Some of the nurses wrote passionately about the challenges of securing adequate care for the women they serve and often questioned the judiciousness of sedating patients or using anesthesia to accomplish exams when the women do not understand what is being done to them.

Table Three

Ethical Concerns Identified by Nurses

WHO HAVE EXPERIENCED SEXUAL ABUSE	
No Response	255 (35.0%)
Inadequate service/funding	116 (15.9%)
Sexuality/contraception	112 (15.4%)
Informed consent	90 (12.3%)
Right to treatment	46 (6.3%)
Child bearing, child rearing, right of persons with special needs to bear/raise children	39 (5.3%)
"Force" exams on unwilling	36 (4.9%)

Summary

When I began the nurse study with my collaborator, I hoped my findings from the earlier study would be refuted. Unfortunately, this is not the case. This second study confirms what the earlier study showed and, because of the sample size and the sophistication of the respondents, confirms the need to focus attention on the data. This study clearly documented several findings that demand immediate attention:

- There are too few primary care providers delivering gynecological and reproductive services to adolescent and adult women with special needs.
- Preparation of healthcare providers is inadequate to provide comprehensive, individualized gynecological and reproductive care for adult and adolescent women with special needs.
- Preparation of professional nurses for the gynecological and reproductive care of adolescent and adult women with special needs is inadequate in both basic and continuing nursing education.
- There is a lack of recognition within the healthcare system of the need to identify and intervene in cases of physical and sexual abuse of adolescent women with special needs.
- STD/HIV screening, testing and treatment are not recognized as important aspects of care for adolescent and adult women with special needs.

I hope these findings will be used to support the enhancement of education efforts for healthcare professionals who serve adolescents and adult women with special needs. Further, it is time that the healthcare system, with its managed care focus, take a hard look at the provision of gynecological and reproductive services for adolescents and women with special needs. As a nurse ethicist, I believe that the time has come to incorporate all vulnerable populations into the nation's healthcare education, planning and programs. EP

Catharine A. Kopac is currently a primary care fellow in the Center for Clinical Bioethics at the Georgetown University Medical Center in Washington, DC. At present she has a research and practice interest in three vulnerable populations: persons with Alzheimer's disease, older adults requiring long-term care and women with developmental disabilities.

This material was excerpted from Kopac, C and Fritz, J (2002). The Availability and Accessibility of Gynecological Services for Women with Developmental Disabilities: A Nursing Perspective, an article submitted to the Journal of Women's Health and Gender Based Medicine.

Resources

American with Disabilities Act, Public Law 101-336, July 26, 1990.

Kopac CA, J Fritz, R Holt. Gynecological and reproductive services for women with developmental disabilities. Clinical Excellence for Nurse Practitioners. 2: 88-95, 1998.

Rowitz L, B Farber. Families with a mentally retarded member, 1959-1986. Presented at the 14th Annual Meeting of the American Public Health Association, Las Vegas, October 1986.

Sulpizi L. Issues in sexuality and gynecologic care of women with developmental disabilities. Journal of Obstetric, Gynecologic, and Neonatal Nursing 25: 609-614, 1996.

VAN CONVERSION DEALERS

ALABAMA

Custom Adaptive Vans & Wheelchairs
3728 1st Ave. North
Birmingham, AL 35222
800-595-7027
Fax: 205-595-7240

ARKANSAS

Presidential Conversions, Inc.
2887 North College Avenue,
Suite B
Fayettesville, AR 72703
(479) 521-8433
Toll Free (888) 521-7733
www.accesspci.com

CALIFORNIA

Mobile Help
613 S. "I" Street
San Bernardino, CA 92410
(909) 383-3883
Fax: (909) 383-3888
E-mail: mobilehelp@earthlink.net
www.mobilehelpinc.com

CONNECTICUT

Advanced Wheels of Technology, Inc.
15 International Drive
East Granby, CT 06026-0908
Toll Free: (877) 943-3573
Full Size and Minivan Conversions.
New & Used Vans Available.
Rentals-wheelchair accessible vans
NMEDA Q.A.P. 5 star dealer.
Visit: awtwheels.com

RIDE-AWAY
Handicap Equipment Corp.
East Hartford, CT
888-743-3292
e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"

DELAWARE

RIDE-AWAY
Handicap Equipment Corp.
Clinton, MD
888-743-3292
e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"

FLORIDA

Action Mobility Products & Services
1925 Tenth Ave. North
Lake Worth, FL 33461
800-432-1459
Ph: 561-582-6500
Fax: 561-582-2921
www.actionmobilityproducts.com
S.E. Florida — Rent or buy a wheelchair accessible minivan by the day/week/month.

C.E.H. Inc.
4457 63 Circle N.
Pinellas Park, FL 33781
(800) 677-0364
Fax: (727) 522-9024
www.liftsandramps.com

Handicapped Driver Services, Inc.
5675 University Boulevard West
Jacksonville, FL 32216
877-HDS-VANS
Fax: 904-730-7272
e-mail jcolnaghi@hdsvans-jax.com
"The South's Most Complete Modifier" Complete inventory list at our web site www.hdsvans.com

GEORGIA

Handicapped Driver Services, Inc.
1349 Old US 41, Suite 160
Marietta, GA 30060
877-HDS-VANS
Fax: 770-425-9535
e-mail: hdsvans@mindspring.com
"The South's Most Complete Modifier" Complete inventory list at our web site www.hdsvans.com

Quail Country Customs, Inc.
6922 Hardup Road
Albany, GA 31707
(229) 432-7258 or
(888) 208-7258
Fax: (229) 883-3141
NMEDA Quality Assured lifts, driving aids, raised roof-doors, Braun, Bruno, Crow River, Ricon, MPS, MPD Wells-Engberg quality sales & service

LOUISIANA

Access Vans of Louisiana, Inc.
17300 Hwy 77 -
P.O. Box 188
Grosse Tete, LA 70740
225-648-3100
Fax: 225-648-3131
www.accessvans.net

MAINE

RIDE-AWAY
Handicap Equipment Corp.
Londonderry, NH
888-743-3292
e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"

LOOK FOR THIS SYMBOL IT'S YOUR GUARANTEE OF QUALITY

It means your adaptive equipment dealer is a member of NMEDA—the National Mobility Equipment Dealers Association—and that your dealer makes a special effort to assure customer Safety, Comfort, and Convenience!

- NMEDA dealers are factory-trained professionals
- NMEDA dealers use only proper tools and high quality materials and follow recommended practices, because the safety welfare of their customers—and everyone on the road—is their first priority.
- A NMEDA customer knows the work on his or her vehicle has been professionally completed by a dedicated, caring and responsible dealer worthy of their trust.

Call our toll-free National Hotline for the location of the NMEDA dealer nearest you:

1-800-833-0427

NATIONAL MOBILITY EQUIPMENT DEALERS ASSOCIATION
11211 N. Nebraska Ave, Suite A-5, Tampa, FL 33612
Phone: 813-977-6603 • Fax: 813-977-6402

Circle #28 or visit www.eparent.com/adinfo

MARYLAND

RIDE-AWAY
Handicap Equipment Corp.
Clinton, MD
888-743-3292
✉e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"
♿ 🚐

MASSACHUSETTS

MOTION AUTOMOTIVE SPECIALITY
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or
(800) 955-949
www.motionautomotive.com
Mobility at it's best.
Complete van & adaptive conversions. Authorized dealer for Braun, Crow River, Ricon & Bruno.Lifts, hand controls, crash tested wheelchair tie-downs.

RIDE-AWAY
Handicap Equipment Corp.
North Attleboro, MA
888-743-3292
e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider. New/used/trade-ins/financing. Featuring Braun Products.
24 Hour Service
5 STAR "QAP"
♿ 🚐

MICHIGAN

MOBILITYWORKS
1965 E. Avis (at Dequindre)
Detroit, MI 48071
800-638-8267
Fax: 248-616-3055
www.mobility-works.com
MobilityWorks has the largest selection in the Midwest of new and used vans and minivans. We buy, sell, and trade vans adapted to your unique needs. Mobile service to your home and a 24 hour emergency line are available.

NEW HAMPSHIRE

RIDE-AWAY
Handicap Equipment Corp.
Londonderry, NH
888-743-3292
✉e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"
♿ 🚐

NEW JERSEY

ARCOLA MOBILITY
51 Kero Road
Carlstadt, NJ 07072
(201) 507-8500
Fax: (201) 507-5372
Large selection of NEW & USED Mini-Vans: side & rear entry. Full size-van conversions W/C Lift & Hand Controls. Tie Downs & Scooter lifters.
♿ 🚐

DRIVE-MASTER CO., INC.
9 Spielman Road
Fairfield, NJ 07004
Phone: 973-808-9709
Fax: 973-808-9713
www.drivemaster.net

MONMOUTH VANS ACCESS & MOBILITY
5105 Routes 33/34 (WALL)
Farmingdale, NJ 07727
(800) 221-0034
Fax (732) 919-0256
Car & Van Mods/Driver or transp.
N.M.E.D.A. "QAP" Certified Van Rentals
www.monmouthvan.com
Stair Glides, Ramps, Pride Jazzy & Scooters.
♿ 🚐

NEW YORK

J. BUSSANI INC.
500 Central Ave
Bethpage, NY 11714
(516) 938-5207
Fax: (516) 938-5263
✉E-mail: jbussani@aol.com
www.jbussani.com
Category V QAP Dealer
♿ 🚐

RIDE-AWAY
Handicap Equipment Corp.
East Hartford, CT
888-743-3292
✉e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"
♿ 🚐

NORTH CAROLINA

TRIAD MOBILITY CENTER
1202 East Mountain Street
Kernersville, NC 27284
336-992-6122
Fax: 336-992-6123
jdskinner@msn.com
www.vannmann.com
Every type of adaptive equipment for vehicles. New and used vans for sale & rent. Wheelchairs & scooters. Home modifications, bathrooms, ramps & stair lifts.
♿ 🚐

VANN MANN ADAPTIVE MOBILITY
6431 Orr Road
Charlotte, NC 28213
704-597-8266
Fax: 704-598-7111
✉jdskinner@msn.com
www.vannmann.com
Every type of adaptive equipment for vehicles. New and used vans for sale & rent. Wheelchairs & scooters. Home modifications, bathrooms, ramps & stair lifts.
♿ 🚐

OHIO

FITZPATRICK ENTERPRISES, INC.
6353 Pontius Road
Groveport, OH 43125
614-497-1000
Fax: 614-497-1863
✉fitzohio@aol.com
♿

Anderson School

Building A Tradition of Service for Over 78 Years

Anderson School provides the highest quality programs possible for children (ages 5-21) and adults with autism and other developmental disabilities. Anderson School is an educational residential community committed to an ongoing and fully integrated support network for their families and guardians. As an organization, Anderson School constantly strives to provide an enriched and positive climate filled with educational, cultural and recreational activities designed to foster continuous growth, independence and social interaction.

Located near historic Hyde Park (approximately 95 miles from midtown Manhattan) on a scenic 100 acre wooded estate overlooking the Hudson River, Anderson School serves all of New York State and welcomes out of state applications.

Now Accepting Referrals

- Residential and day students welcome
- Students accepted throughout the year

Call Kate Haas, Director of Admissions (845) 889-4034 Ext. 534
4885 Route 9, Box 367, Staatsburg, New York 12580-0367
www.andersonschool.org E-mail: mespie206@aol.com

Circle #17 or visit www.eparent.com/adinfo

KEY MOBILITY SERVICES
2020 North Detroit St.
Xenia, OH 45385
(800) 539-5438
Fax: (937)374-4460
www.keymobility.com

MOBILITYWORKS
810 Moe Drive
Akron, OH 44310
800-638-8267
Fax:330-633-0330
www.mobility-works.com
MobilityWorks has the largest selection in the Midwest of new and used vans and minivans. We buy, sell, and trade vans adapted to your unique needs. Mobile service to your home and a 24 hour emergency line are available.

TRI-STATE MOBILITY
940 Cleveland SW
Canton, OH 44707
(800) 343-3150
Fax: (330) 489-6661

Also: 2735 Dore Street
Toledo, OH 43609
(800) 345-3150
Fax: (419) 531-6668

Also: 165 Freemans Bridge Road
Scotia, NY 12302
(800) 841-3150

Also: 1126 Third St.
North Versailles, PA 15137
(866) 347-3150
✉E-mail: www.tristate@raex.com
Website: www.tristatemobility.com

RHODE ISLAND

RIDE-AWAY
Handicap Equipment Corp.
North Attleboro, MA
888-743-3292
✉e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"

TENNESSEE

ACCESS INDUSTRIES, INC.
2509 Summer Avenue
Memphis, TN 38112
(901) 323-5438
Fax: (901) 323-5559
www.access-ind.com
Sales • Service • Rentals
Five Star Quality Assurance Dealer

TEXAS

Advanced Mobility Systems of Texas
2110 North Beach Street
Fort Worth, Texas 76111
817-429-1273
Fax : 817-838-0586
✉e-mail: goadvanced@aol.com
www.advancedmobility.net

LIFT-AIDS, INC.
1500 Westpark Way
Euless, TX 76040
(817) 835-0035 or
(800) 351-5438
Mobility specialist for physically challenged since 1968. Largest wheelchair lift installer in Dallas/Ft. Worth Metro area. Five Star NMEDA member. Dealer for Braun/Crow River, Ricon, MPS, Lowered floor Mini-Vans, Bruno, Handicaps, Inc. Call for demonstration.
www.lift-aids.com

VERMONT

RIDE-AWAY
Handicap Equipment Corp.
Essex Junction, VT
888-743-3292
✉e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"

VIRGINIA

RIDE-AWAY
Handicap Equipment Corp.
Clinton, MD
888-743-3292
✉e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"

WEST VIRGINIA

RIDE-AWAY
Handicap Equipment Corp.
Clinton, MD
888-743-3292
✉e-mail: ride-away.com
The East Coasts Largest Adaptive Equipment Provider.
New/used/trade-ins/financing.
Featuring Braun Products.
24 Hour Service
5 STAR "QAP"

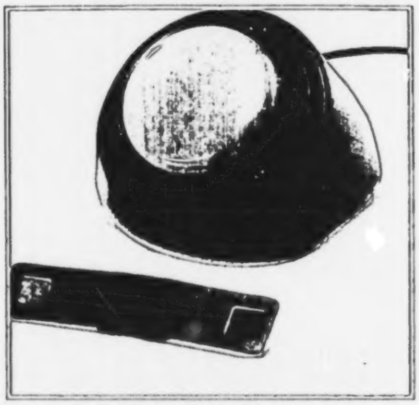
FREEDOM
FREEDOM Concepts Inc.
"MAKING MOBILITY A REALITY"™
REAR STEERING
TANDEM
JOURNEY

www.freedomconcepts.com

HANDCRAFTED WITH PRIDE, QUALITY AND INGENUITY AT A REASONABLE PRICE

FREEDOM CONCEPTS INC.
45117 RPO REGENT, WINNIPEG, MB R2C 5C7
PHONE: 1-800-661-9915 FAX: 204-654-1149
EMAIL: MOBILITY@FREEDOMCONCEPTS.COM

Circle #40 or visit www.eparent.com/adinfo



JELLY BEAN® BOOSTER SWITCH

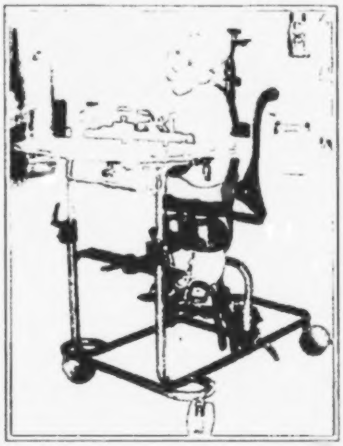
The Jelly Bean Booster Switch has an angled base for easy access and provides audible feedback with each press. It comes with an AbleLink Connectables® base and Snap Track connector. The Connectables base allows the switch to be easily detached and reattached from mounted or non-mounted locations. The Snap Track connector allows multiple Jelly Bean Booster Switches to link together, creating a customized system. The Jelly Bean Booster Switch is available with red, pink, yellow, green, blue, purple and black activation areas.

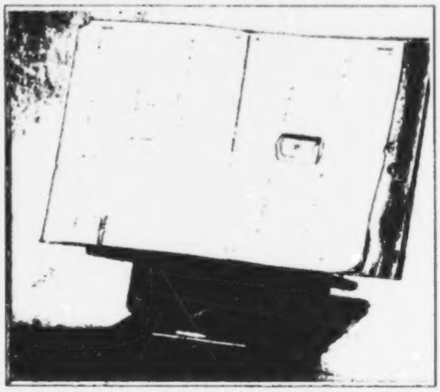
AbleNet, 1081 Tenth Avenue SE, Minneapolis, MN 55414-1312; Phone: (800) 322-0956, (612) 379-0956; (612) 397-9143; Web site: http://www.ablenetinc.com; E-mail: customerservice@ablenetinc.com

EASYSTAND® MAGICIAN EI®

The EasyStand Magician EI is a fully adjustable standing aid that can be comfortably positioned anywhere between sitting and standing. It provides a wrap-around seat and back support that conform to the child. The Magician EI also comes with side supports, knee supports, foot holders with foot straps, seat belt, clear acrylic tray and four locking casters. This standing aid has a tubular frame, a back angle indicator that allows for precise positioning, and an ultra-low shear lifting mechanism that mimics natural body movement.

Altimate Medical, PO Box 180, 262 West 1st Street, Morton, MN 56270; Phone: (800) 342-8968, (507) 697-6393; Fax: (877) 342-8986, (507) 697-6900; Web site: http://www.easystand.com; E-mail: info@easystand.com

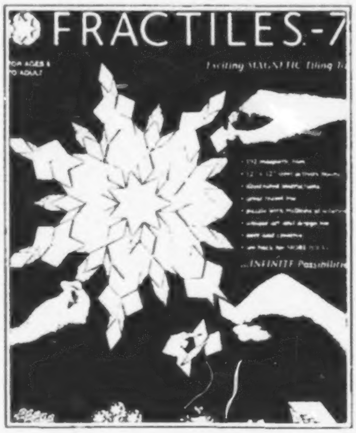




ATLAS™ ULTRA

The Atlas Ultra is an ergonomically designed book and copy holder that provides an adjustable viewing height and angle for comfortable reading. Made of Trespa®, a strong wood product, this book holder comes with four page-stoppers to help keep the book open and an optional line guide to hold a place on the page. Color choices include raspberry, lemon, stone beige, sunflower and black.

Dainoff Designs, Inc., 8606 Empire Court,
Cincinnati, OH 45231-4913;
Phone: (800)-438-2852; Fax: (513) 522-3611;
Web site: http://www.bookandcopyholders.com;
E-mail: info@bookandcopyholders.com



FRACTILES-7

Fractiles-7 is a flexible magnetic tile toy with angles based on the number seven. These red, yellow and blue diamond-shaped tiles are easily manipulated to create patterns such as starbursts, butterflies and 3-D illusions. Fractiles-7 can be used as an aid in building pattern recognition, visual analysis and fine motor skills. These magnetic tiles are maneuvered on a sturdy black textured steel activity board. The tiles and board can be transported and stored in the record-jacket-style package.

FRACTILES, Inc., 2525 Arapahoe Ave., Suite E4-110, Boulder, CO 80302; Phone: (303) 541-0930; Fax: (303) 442-7776; Web site: http://www.fractiles.com; E-mail: fractiles@fractiles.com

---

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

In CONTROL with COMFORT!

You'll feel the difference the minute you start using MYDESC. The product's ergonomic design allows you to easily swivel and tilt the desktop in all directions.

1-800-4 MYDESC

www.mydesc.com
Santa Clara, CA 95056

Circle #1

WHEELCHAIR PARTS. AFFORDABLE PRICES.

If you are a parent, school, or institution, now you can buy wheelchair parts at affordable prices. A full line of wheelchair replacement parts, as well as other useful items for wheelchair users is available online at

www.affordableoption.com
1-877-914-1830

AO Affordable Option Health Care Products

Circle #2

Diaper Doublers™

Diaper Doublers inserts that make cloth or disposable diapers more efficient, pulling moisture away from a child's tender skin.

- Trim & Comfortable
- Overnight Protection
- Absorbency without Bulk
- Latex-Free for Sensitive Skin

www.DiaperDoubler.com
1-800-335-4434
Toll-Free Phone Orders

"The Drier Way to Diaper"™

Circle #3

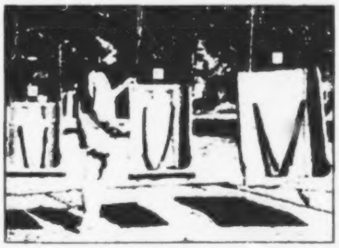
freedom

what is your definition?

call us today!

1.800.661.9915
www.freedomconcepts.com

Circle #4



Let our well-known Swing Seats bring swinging enjoyment to your family.

STRONG but soft plastic with a safety harness and ropes that adjust to BOTH length and rake, a very IMPORTANT feature.

TFH (USA) 800-467-6222

Circle #5

INTRODUCING

the Invacare® Top End® Terminator® Jr. for kids who are going places!

A super stable, adjustable chair that grows—and that kids can move all by themselves.

Circle #6

Natural Access™

Expand your horizons with the Landeez All-Terrain Wheelchair!

Rolls easily over sand, snow, gravel, and uneven terrain, so you can enjoy the outdoors

For more info 800-411-7789 or visit www.landeez.com

Circle #7

MARKETPLACE

ATTORNEY

Attorney Richard Gottesman
(800)295-1107
gottesman@law.com
Cerebral Palsy, Brachial Plexus/Erb's Palsy and Childbirth Injuries

BEACH WHEELCHAIR

Affordable Independence in the Great Outdoors!

The Features Make All the Difference!

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure

CYCLES

Cycles for Virtually Every Special Need & Age

Amputations, Cerebral Palsy, Spina Bifida, Visual Impairments/ Blindness, and many others

You Can Even Earn Your Own Cycle!
806-894-5700 FAX: 806-894-1238

Check us out on the Web...
http://www.rocknrollcycles.com

BOOKS/VIDEO

Poetry Books about Autism
A mother's and poet's perspective; "Seasons of Love, Seasons of Loss"
About diagnosis and discovery "Letting Go" on placing a son in a group home.
$7.00 for each book (includes S&H)
Mail orders to: Connie Post
P.O. Box 5591 Pleasanton, CA 9456[illegible]
Checks to "Connie Post".
Get order forms at www.poetrypost.com

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends.
Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg,
PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

EQUIPMENT DEALERS

American
Discount Medical

Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available.
NY State Medicaid Provider.
Resource information:
www.medmarket.com
e-mail: info@archhp.com

Ask about our Youth Brief sample pack. Only $5.99!

HDIS **FREE CATALOG**

Call Today!
1-800-2MY-HOME™
(1-800-269-4663)

MONITORING SYSTEM

Care Electronics Inc.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price.
Call for FREE CATALOG

RESOURCES

EXCEPTIONAL PARENT

Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores All Across America.
Every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books.
$4.95 Cover Price.

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services.
The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources.
Just $19.95
(plus shipping/ handling).
To order, call 1-800-535-1910.

SWINGS

Portable Swing Stand

Therapy Swings

Safe, strong comforting & affordable for all your swinging and spinning needs

For more information contact
Take-A-Swing LLC
602-451-5544 • www.takeaswing.com

MARKETPLACE

SWITCHES

BUBBLES™ SWITCHES — for those who have difficulty using ordinary switches. Touch-sensitive, or it can be set so the hand only needs to pass near the switch! Convenient dome shape.

MINIMAL MOTION™ SPLINT SWITCH KITS — touch-sensitive switch pads to mount directly on hand splints.

EQUAL ACCESS COMPUTER TECHNOLOGY, INC. 978-466-9191
222 Grant Way, Lancaster, MA 01523
Email: eact@world.std.com

VAN CONVERSION DEALERS

MASSACHUSETTS

Motion Automotive Specialty
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—
Day, Week or Month.

To Advertise in Marketplace Contact:

Barbara Nastro

Tel: (908) 534-6366

Fax: (908) 534-6941

Ability Camp Inc.

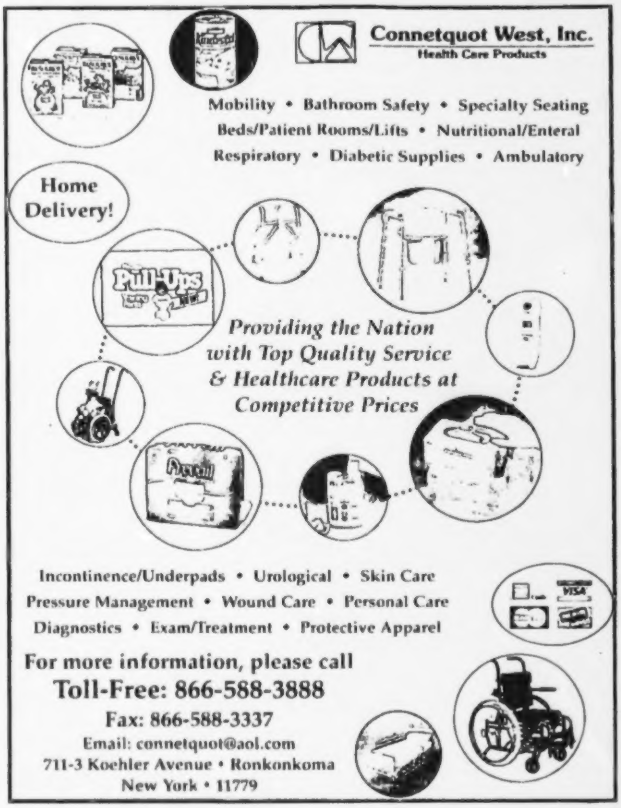
Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.



Connetquot West, Inc.
Health Care Products

Mobility • Bathroom Safety • Specialty Seating
Beds/Patient Rooms/Lifts • Nutritional/Enteral
Respiratory • Diabetic Supplies • Ambulatory

Home Delivery!

Providing the Nation with Top Quality Service & Healthcare Products at Competitive Prices

Incontinence/Underpads • Urological • Skin Care
Pressure Management • Wound Care • Personal Care
Diagnostics • Exam/Treatment • Protective Apparel

For more information, please call
Toll-Free: 866-588-3888
Fax: 866-588-3337
Email: connetquot@aol.com
711-3 Koehler Avenue • Ronkonkoma
New York • 11779

Circle #28 or visit www.eparent.com/adinfo

The Association for Driver Rehabilitation Specialists
ADED

ADED - The Association for Driver Rehabilitation Specialists - is devoted to the support of professionals working in the field of driver education and transportation equipment modification for persons with disabilities.

For membership information or to locate a driver rehabilitation specialist in your area contact:

ADED
711 S. Vienna St.
Ruston, LA 71270
(800) 290-2344 US Only
(318) 257-5055

Visit us at: http://www.aded.net

Circle #21 or visit www.eparent.com/adinfo

What I Love About Sarah

by Bridget Kramer

Bridget Kramer, (r.) 11, and her sister, Sarah, 9, can often be found spending time together.

I'd like to tell you about someone who isn't like most people. In her own way, she's very special. Her name is Sarah and she is my little sister. She is 9 years old and she has mental retardation and cerebral palsy. She is always happy unless she's sick. She can't walk or talk but she has a way to communicate. Whenever she sucks her index and middle fingers on her left hand, that means she's hungry. Another way she isn't like other kids is that she loves to take a bath. She always gets excited when she's getting ready.

Sometimes my mom and dad are sad when she cries a lot. When this happens, I go in and sit with her. I don't think I've ever lived a day without thinking about her. She still has to wear a bib and diaper. She wears glasses, too. She drinks nutritional supplements every day. Banana and vanilla are her favorite flavors.

She can make the whole family laugh so hard, but she has never made me cry. It made my mom and dad cry when they found out that she was retarded. Sometimes I wish that she could be normal, but I know that I can't change it; that's when I love her most. All of my friends think she is really cute. It makes me feel happy when they say that. I know then that they're not scared of her. EP

MOM AND DAD'S TURN

Barbie Garrison and Paul Kramer are Bridget and Sarah's parents

"We recently attended a monthly meeting of our Special Parents group where we heard about 'chronic sorrow.' Bridget wanted to stay with us and hear the presentation rather than hang out with the other children. Many issues that surround having a child or sibling with special needs were discussed and Bridget was attentive to the various feelings described.

"We found that Sarah was special when Bridget was almost 3 years old. At the time, we explained Sarah's condition in a way that Bridget could understand. Her interpretation was, 'Sarah isn't growing up right. I grew up fast; Sarah is growing up slow.'

"When we returned home, we were reading our most recent issue of EP, and I told Bridget about the Children's Page. She immediately set to writing and produced the touching sentiments included here.

"Until this time, we weren't really sure how well Bridget understood her sister or how deep her feelings about Sarah were. We are grateful for this opportunity for Bridget to express her feelings. We are also happy that we have the blessing of two wonderful children."

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number, and e-mail address! ***Now on the Web!*** We now include **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

A World Without Limits For Hearts That Know No Bounds

Life's A Trip – Travel In Style

Financial Assistance Comprehensive Adaptive Equipment Information

- $1,000 for the installation of adaptive equipment.[1]
- $200 for alerting devices, lumbar seats and running boards.[2]
- Solid information about selecting and installing adaptive equipment.

Ford Motor Company Products
Ford, Lincoln and Mercury cars, vans and light trucks of proven quality, durability, performance and value.

Ford Credit Mobility Financing
Flexible finance terms on both the vehicle and the adaptive equipment for qualified customers enrolled in the Ford Mobility Motoring Program.

Ford Motor Company
MOBILITY
MOTORING
LINCOLN Ford Mercury

Order Your Ford Mobility Motoring Information Kit Today!

From Our Web Site:
www.ford.com/mobilitymotoring

From Our Telephone Response Center:
1-800-952-2248 or TTY 1-800-833-0312

[1] The Ford Mobility Motoring Program will reimburse for the exact amount of the adaptation up to a maximum of $[illegible]00 on adaptive equipment and up to a maximum of $200 on alerting devices, lumbar support and running boards when you take new retail delivery of a 2001, 2002 or 2003 Ford, Lincoln or Mercury vehicle by August 31, 2002. Total reimbursement not to exceed $1,000.

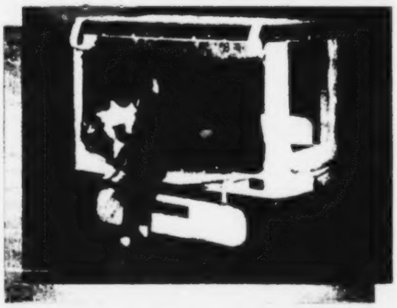
[2] Factory installed air conditioning, lumbar seats, running boards and power windows options are not eligible for Ford Mobility Motoring Program assistance.

Circle #38 or visit www.eparent.com/adinfo

04

A Better Bedtime Story

The Vail Enclosed Bed



Ask about Our Decorator Accessories.

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

[illegible]

[illegible]

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

Sheri Wittmer
Sandusky, Ohio

642

Circle #76 or visit www.eparent.com/adinfo

Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed —while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for your child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt.

Plus, we provide assistance in obtaining insurance approval.

Available from home health-care products dealers, or direct from the manufacturer.

For a FREE catalog, call:
1-800-235-VAIL

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent

JUNE 2002
$4.95

ROLE MODEL BILL PORTER Shares the Secret of His Success

TECHNOLOGY

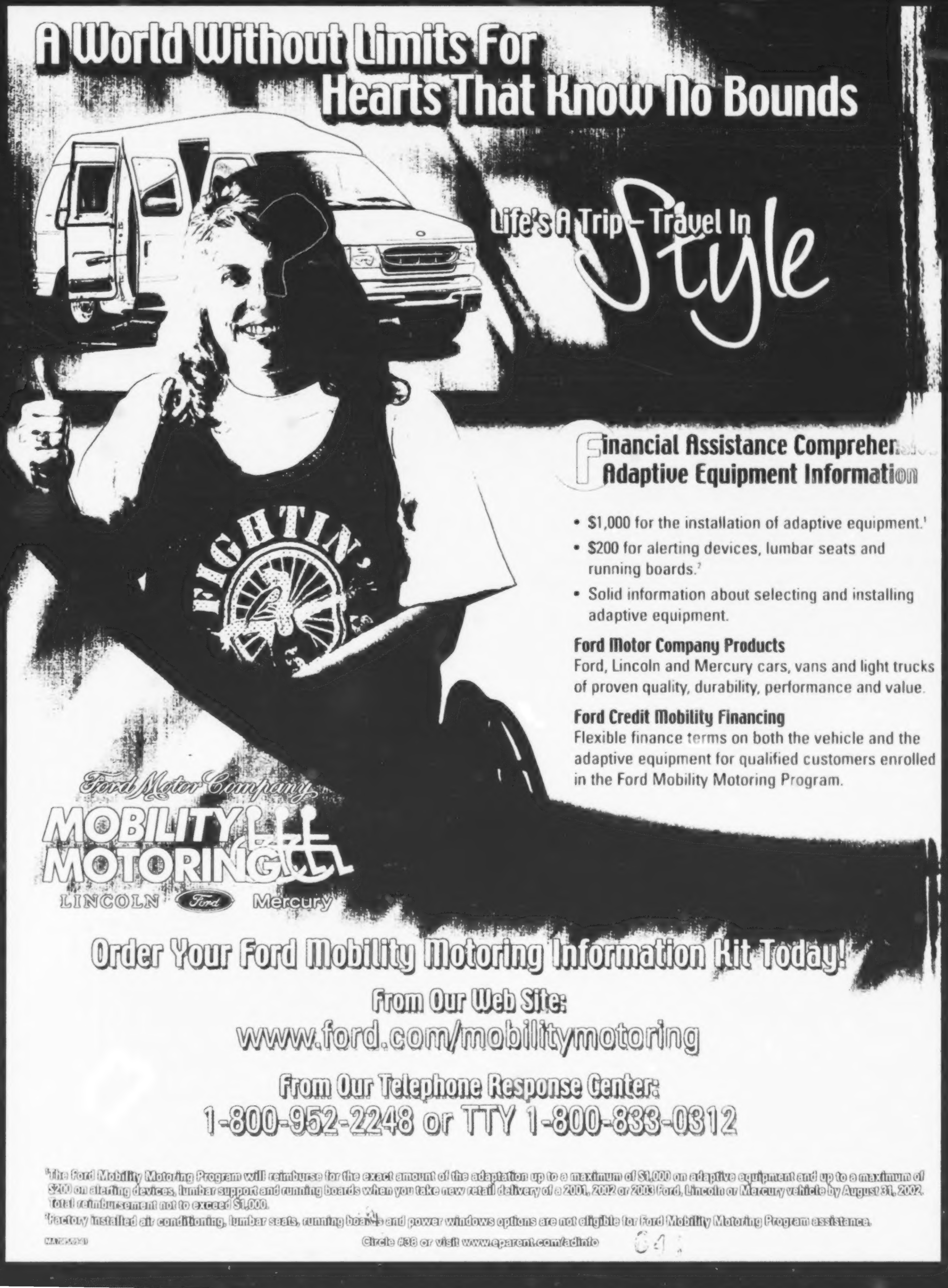
Research on Traumatic Brain Injury

Adaptive Track and Field

www.eparent.com

#############################5-DIGIT 22201
22201AQU111CUDO ZNI02
ACQUISITIONS
ACQUISITIONS
COUNCIL FOR EXCEPT R=4175
1110 N GLEBE RD STE 300 S104 P5
ARLINGTON VA 22201-4795

BEST COPY AVAILABLE



A World Without Limits For Hearts That Know No Bounds

Life's A Trip – Travel In Style

Financial Assistance Comprehen Adaptive Equipment Informati

- $1,000 for the installation of adaptive equipment.[1]
- $200 for alerting devices, lumbar seats and running boards.[2]
- Solid information about selecting and installing adaptive equipment.

Ford Motor Company Products
Ford, Lincoln and Mercury cars, vans and light trucks of proven quality, durability, performance and value.

Ford Credit Mobility Financing
Flexible finance terms on both the vehicle and the adaptive equipment for qualified customers enrolled in the Ford Mobility Motoring Program.

Order Your Ford Mobility Motoring Information Kit Today!

From Our Web Site:

www.ford.com/mobilitymotoring

From Our Telephone Response Center:

1-800-952-2248 or TTY 1-800-833-0312

---

[1] The Ford Mobility Motoring Program will reimburse for the exact amount of the adaptation up to a maximum of $1,000 on adaptive equipment and up to a maximum of $200 on alerting devices, lumbar support and running boards when you take new retail delivery of a 2001, 2002 or 2003 Ford, Lincoln or Mercury vehicle by August 31, 2002. Total reimbursement not to exceed $1,000.

[2] Factory installed air conditioning, lumbar seats, running boards and power windows options are not eligible for Ford Mobility Motoring Program assistance.

MA7025-0241

Circle #38 or visit www.eparent.com/adinfo

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

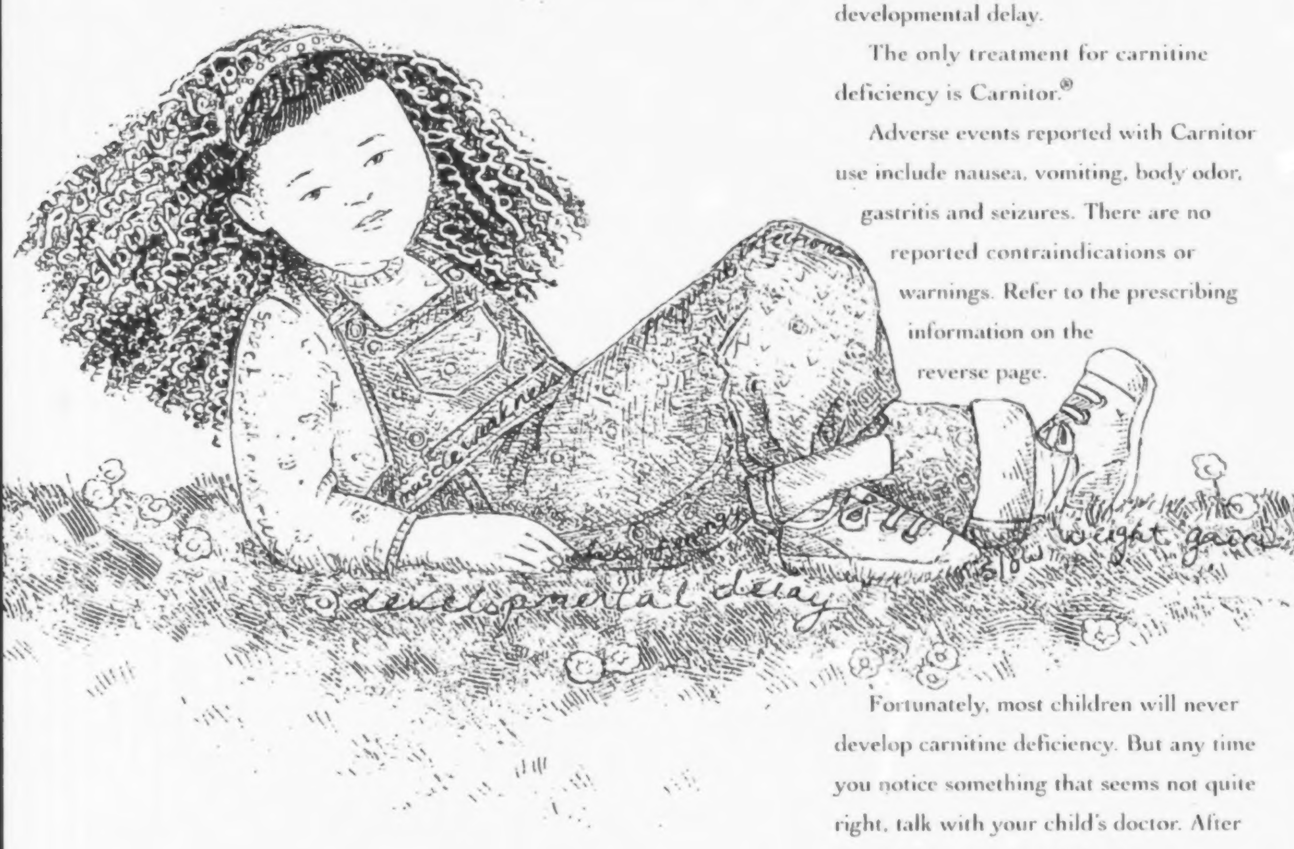
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Circle #61 or visit www.eparent.com/adinfo

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 μmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #70 or visit www.eparent.com/adinfo

Preparing wholesome food for our children for over 30 years.

Try one of our eight varieties and let us share with you the

peace of mind

and well-being that comes from EDENSOY Organic Soymilk.

EDENSOY Light
ORGANIC SOYMILK
EDEN
EDENSOY EXTRA
ORGANIC SOYMILK
EDEN
EDENBLEND
Rice & Soy
EDEN
EDENSOY
ORGANIC SOYMILK
EDEN

Save 50¢

On any EDENSOY®
Single liter or 3 pack

Consumer: Coupon good only in USA on purchase of brands/size indicated. Void if copied, transferred, prohibited or regulated. Retailer: Eden Foods, Inc. will reimburse you for the face value of this coupon plus 8¢ handling if redeemed in compliance with our redemption policy. Copy sent upon request. Invoices proving purchase of sufficient stock to cover coupons must be shown on request. Face value 001¢. Mail coupon to: CMS Dept. [illegible]; One Fawcett Drive, Del Rio, Texas [illegible]

Redeemable at retail stores only.

10633

EDEN.

Manufacturer's Coupon | Expires 10-31-02

5 24182 00050 9 (8101) 0 10633 1002

648

© 2002 Eden Foods, Inc.

Call for a free Edensoy brochure **888.424.EDEN** or visit us online **www.edenfoods.com**

Circle #35 or visit www.eparent.com/adinfo

contents

JUNE 2002 • VOLUME 32, ISSUE 6

40

TECHNOLOGY
In Education & Daily Living

28 Working Together: Computer Technology and People with Mobility & Sensory Impairments
by Sheryl Burgstahler, PhD, and Dan Comden
Overcoming barriers with adaptive technology.

38 Technologies for People with Cognitive Disabilities
by Vanessa B. Ira
The Coleman Institute seeks integration of high tech into daily life.

40 Thinking Readers
by Lucinda M. O'Neill and Bridget Dalton, EdD
Technology can make reading fun and easy for children with cognitive disabilities.

44 Low Tech—No Tech
by Project Participate
Simple ideas that won't strain the budget, or the brain.

46 Assistive Technology Study Begins
by Vince Wetzel
The NIDRR awards a grant to a community-based organization for research on benefits of assistive technology.

50 Legislative Update
by Laura Noble
Federal assistive technology legislation.

55 Tech Talk: Where can I learn about computer technology that might benefit my child?
by Sheryl Burgstahler, PhD
Introducing a new monthly column on technology.

EP and The New York Yankees

Sponsor Disability Awareness Night at Yankee Stadium July 3rd, 2002.

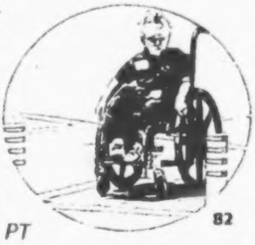
Wednesday, July 3rd, The New York Yankees in coordination with EP Magazine will hold the 1st Annual Disability Awareness Night at Yankee Stadium. Issues will be distributed and special subscription offers will be availabe. Come show your support for the Yankees and Exceptional Parent.

FEATURES

58 Management and Control of Refractory Seizures in the MR/DD Population
by Fern R. Potvin, MPA
A summary of presentations by experts and advocates in the field.

64 Role Model No Excuse for Failure – THE BILL PORTER STORY
by Joseph M. Valenzano, Jr., and Natalie E. Gerber, PhD
The story of an exceptional salesman; including an interview with Shelly Brady, the author of *Ten Things I learned from Bill Porter.*

72 A Medical Home Design for Children with Special Needs
by Elizabeth Wehr
Vermont doctors and parents create a system to coordinate care.


82

82 Sports Corner
On Track with Track and Field
by Carol Keller, PT
The first installment of an ongoing column contributed by the NDSA.

SPECIAL REPORT:

97 Oral Healthcare Part XII Oral Signs of Systemic Disease
by Michael A. Kahn, DDS and Jerry E. Bouquet, DDS, MS
Sometimes the mouth can be a window to the body's health.

SPECIAL REPORT:

105 Informing, Empowering and Keeping Parents Involved: A Four Part Series
Part1 The Beginning: How parents move forward and make choices after diagnosis.
by Elizabeth King Gerlach

COVER: Bill Porter, outstanding salesperson, is this month's Role Model and subject of new book by his business associate, Shelly Brady, and soon-to-be-released TV movie. Mr. Porter, who has cerebral palsy, has been a case study in success and an inspiration to many. Read EP's profile in "No Excuse for Failure" starting on page 64.

EP
Exceptional Parent

contents

DEPARTMENTS

12 **Editor's Desk**

14 **Letters**

20 **Search & Respond**

22 **Book Notes**
by Joy Liebskind
From Emotions to Advocacy

62 **Ask the Doctor**
by Cynthia L. Harden, MD
"Women and Epilepsy: Breakthrough Seizures"

80 **Parent Perspective**
by Lori Pederson
"Snapshots of Your Life"

84 **Research Reflections**
by Jan Blacher
"Traumatic Brain Injury"

90 **Organizational Spotlight**
The Muscular Dystrophy Family Foundation, Inc.

94 **Familiar Faces**

110 **EP Library**

112 **New Products**

116 **Children's Page**
by Lee Lipschutz
The Miracle of Life

EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTH-CARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy-Ed Corp., dba *EXCEPTIONAL PARENT Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved.

Copyright ©2002 by Psy-Ed Corp. *EXCEPTIONAL PARENT*® is a registered trademark of the Psy-Ed Corp.

Postmaster: Please send address changes to: *EXCEPTIONAL PARENT*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *EXCEPTIONAL PARENT*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *EXCEPTIONAL PARENT*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #4006 0754. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

EXCEPTIONAL PARENT neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
While hyperbaric oxygen is effective therapy in certain conditions it is currently considered an alternative therapy for CP and other "brain insult" conditions. Readers are advised to discuss the advisability of HBOT with their primary or specialty healthcare providers as well as to study the current literature.

—Rick Rader, MD

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

MITCHELL F. BRIN, MD, Vice President, Botox, Allergan, Irvine, CA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics , Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof. Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

HARILYN ROUSSO, ACSW, Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

THERESA VARNET, MSW, JD, Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

Diagnosing and Treating Childhood Movement Disorders

FREE Ask the Expert Teleconference and Web Seminar

http://www.eparent.com

June 26, 2002 - 6 PM - 7 PM (EDT)
(5 PM CDT, 4 PM MDT and 3 PM PDT)

July 10, 2002 - 8 PM - 9 PM (EDT)
(7 PM CDT, 6 PM MDT and 5 PM PDT)

Featuring:

A. Leland Albright, MD

Professor of Neurosurgery, University of Pittsburgh School of Medicine; Chief, Department of Pediatric Neurosurgery, Children's Hospital of Pittsburgh.

Terence Edgar, MD

Associate Professor of Neurology & Pediatrics; Director of Neuromuscular & Movement Disorders Programs, Arkansas Children's Hospital.

Open to Families & Caregivers!

Learn how to differentiate between childhood movement disorders and associated symptoms. Additionally, the experts will discuss available treatment options, outcomes and resources for more information. Following the brief presentation, the experts will be available for questions on-line and via telephone hook-up.

EP Exceptional Parent

UCP Understanding Disabilities Creating Opportunities

Medtronic When Life Depends on Medical Technology

Register online or call today to reserve your place:

Sponsored, in part, by an educational grant from Medtronic, Inc.

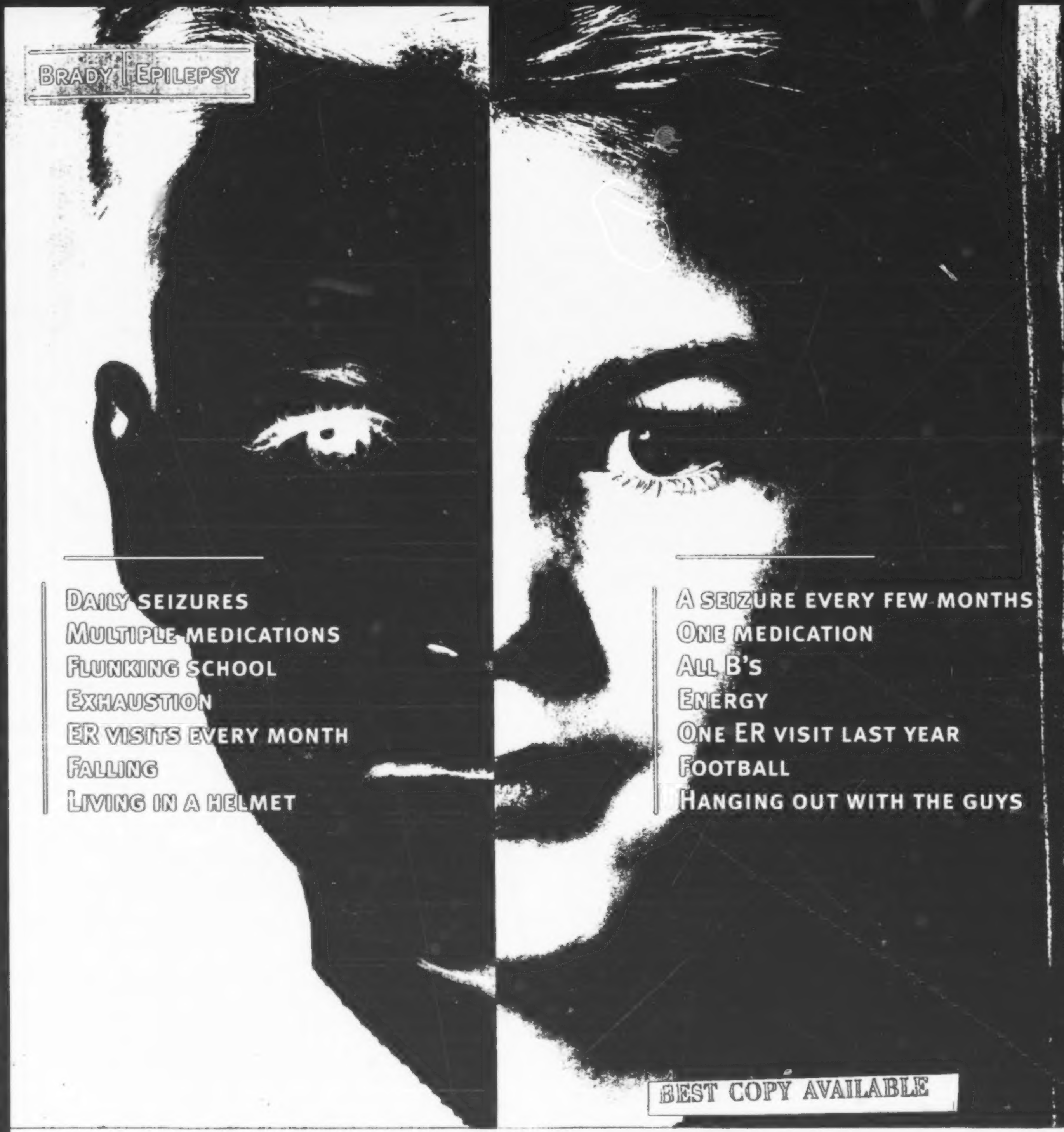
Register now for FREE

To register visit www.eparent.com or call 800-EPARENT ext. 203. RSVP by: June 21st 2002
Remember to indicate which program you are interested in.

The events can be easily accessed by telephone and via the Web – through EP's site (www.eparent.com) and the United Cerebral Palsy site (www.ucp.org).

Log on to EParent.com for simple instructions and more details on how to participate.

Circle #45 or visit www.eparent.com/adinfo


BRADY | EPILEPSY
DAILY SEIZURES
MULTIPLE MEDICATIONS
FLUNKING SCHOOL
EXHAUSTION
ER VISITS EVERY MONTH
FALLING
LIVING IN A HELMET
A SEIZURE EVERY FEW MONTHS
ONE MEDICATION
ALL B'S
ENERGY
ONE ER VISIT LAST YEAR
FOOTBALL
HANGING OUT WITH THE GUYS

BEST COPY AVAILABLE

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

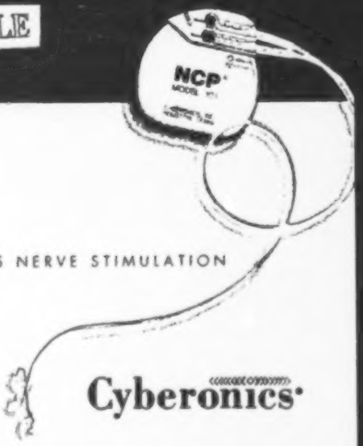
So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

BEST COPY AVAILABLE



VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS THERAPY™

VAGUS NERVE STIMULATION

Cyberonics®

Circle #30 or visit www.eparent.com/adinfo

EXECUTIVE SUMMARY[1]
SAFETY INFORMATION
FOR THE NCP® SYSTEM

INTENDED USE / INDICATIONS – UNITED STATES

The NCP System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures which are refractory to antiepileptic medications.

CONTRAINDICATIONS

- The NCP System cannot be used in patients after a bilateral or left cervical vagotomy.
- Do not use short-wave diathermy, microwave diathermy, or therapeutic ultrasound diathermy on patients implanted with the NCP System. Diagnostic ultrasound is not included in this contraindication.

WARNINGS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals. This is not intended to serve as a substitute for the complete NCP System Physician's Manual.

⚠ The **safety and efficacy** of the NCP System has not been established for uses not covered in the "Intended Use/ Indications" section of the manual.

⚠ The safety and efficacy of the NCP System treatment has not been established for stimulation of the **right vagus nerve** or of any other nerve, muscle, or tissue.

⚠ **Excessive stimulation** at a combination of high frequency (≥ 50 Hz) and an excess duty cycle (that is, one that occurs when ON time is greater than OFF time) has resulted in degenerative nerve damage in laboratory animals. An excess duty cycle can be produced by continuous or frequent magnet activation (> 8 hours), as determined by animal studies. Cyberonics recommends against stimulation at these combinations of ranges.

⚠ **Aspiration** may result from the increased swallowing difficulties reported by some patients during stimulation. Patients who have **pre-existing swallowing difficulties** are at greater risk for aspiration.

⚠ **Device malfunction** could cause painful stimulation or direct current stimulation. Either event could cause nerve damage and other associated problems. Patients should be instructed to use the magnet to stop stimulation if they suspect a malfunction, and then to contact their physician immediately for further evaluation. Prompt surgical intervention may be required if a malfunction occurs.

⚠ Susceptible patients with predisposed cardiac conduction systems (re-entry pathway) have not been studied as part of controlled clinical trials to establish the safety of NCP system treatment in these patients. Evaluation by a cardiologist is recommended if the family history, patient history, or electrocardiogram suggests an abnormal cardiac conduction pathway. Serum electrolytes, magnesium, and calcium should be documented before implantation. Post-implant electrocardiograms and Holter monitoring are recommended if clinically indicated.

⚠ **Sudden unexplained death in epilepsy (SUDEP):** Through August 1996, 10 sudden and unexplained deaths (definite, probable, and possible) were recorded among the 1,000 patients implanted and treated with the NCP device. During this period, these patients had accumulated 2,017 patient-years of exposure. Some of these deaths could represent seizure-related deaths in which the seizure was not observed, at night, for example. This number represents an incidence of 5.0 definite, probable, and possible SUDEP deaths per 1,000 patient-years. Although this rate exceeds that expected in a healthy (nonepileptic) population matched for age and sex, it is within the range of estimates for epilepsy patients not receiving vagus nerve stimulation, ranging from 1.3 SUDEP deaths for the general population of patients with epilepsy, to 3.5 (for definite and probable) for a recently studied antiepileptic drug (AED) clinical trial population similar to the NCP System clinical cohort, to 9.3 for patients with partial onset epilepsy.

⚠ **The NCP device is not curative:** Physicians should warn patients that the NCP System is not a cure for epilepsy and that since seizures may occur unexpectedly, patients should consult with a physician before engaging in un-supervised activities, such as driving, swimming, and bathing, and in strenuous sports that could harm them or others.

⚠ **Obstructive Sleep Apnea:** Patients with obstructive sleep apnea (OSA) may have increased apneic events during stimulation. Cyberonics recommends care when treating patients with preexisting OSA. Lowering stimulus frequency or prolonging OFF time may prevent exacerbation of OSA.

PRECAUTIONS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals.

⚠ **Laryngeal irritation** may result from stimulation. **Patients who smoke** may have an increased risk of laryngeal irritation.

⚠ **Dyspnea** may result from stimulation. **Patients with chronic obstructive pulmonary disease** may have an increased risk of dyspnea.

⚠ It is important to follow **recommended Implantation procedures and intraoperative product testing** described in this manual. During the intraoperative Lead Test, rare incidents of bradycardia and/or asystole have occurred. As of October 1998, approximately 3,000 patients had been implanted with the NCP System. Four of these patients were reported to have experienced **bradycardia and/or asystole** during the intraoperative Lead Test. All four patients recovered without sequelae. One of the four patients was implanted with the NCP System. There were no postoperative or VNS-treatment-related cardiac adverse events later reported for that patient. No similar events were reported to have occurred during the clinical studies at the time of implantation or during treatment. The safety of this therapy has not been systematically established for patients experiencing bradycardia or asystole during NCP System implantation.

⚠ **Reversal of lead polarity has been associated with an increased chance of bradycardia** in animal studies. It is important to make sure that the Lead connector pins are correctly inserted (white marker to + connection) into the Pulse Generator header.

⚠ It is important to follow **infection control procedures**. Infections related to any implanted device are difficult to treat and may require that the device be explanted. Cyberonics recommends that the patient be given antibiotics preoperatively. The surgeon should ensure that all instruments, including the NCP Tunneling Tool, are sterile prior to the operation.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve** in the neck area inside the carotid sheath.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve below where the superior and inferior cervical cardiac branches separate from the vagus nerve.**

⚠ **A neck brace** can be used by the patient for the first week to help ensure proper Bipolar Lead stabilization.

Environmental and Medical Therapy Hazards

⚠ Patients should exercise reasonable caution in avoiding devices that generate a **strong electric or magnetic field.** (For examples, see the "Other Environmental Hazards" section of the Physician's Manual.) If a Pulse Generator ceases operation while in the presence of electromagnetic interference (EMI), moving away from the source may allow it to return to its normal mode of operation.

⚠ NCP System operation **should always be checked** by performing device diagnostics after any of the procedures mentioned in the Physician's Manual.

⚠ Because of where the Pulse Generator is implanted in the chest, **patients may need to be specially positioned in mammography equipment for clear imaging.** Otherwise, the device may be seen as a shadow on the mammogram. (Most routine diagnostic procedures, such as fluoroscopy and x-radiography, are not expected to affect system operation.)

⚠ **Therapeutic radiation** may damage the Pulse Generator's circuitry, although no testing has been done to date and no definite information on radiation effects is available. Sources of such radiation include therapeutic x-rays, cobalt machines, and linear accelerators. The radiation effect is cumulative, with the total dosage determining the extent of damage. The effects of exposure to such radiation can range from a temporary disturbance to permanent damage, and may not be detectable immediately.

⚠ **External defibrillation** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for external defibrillation.

⚠ **Electrocautery surgery** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for electrocautery surgery.

⚠ **Magnetic resonance imaging** (MRI) should not be performed with a magnetic resonance body coil in the transmit mode. The heat induced in the Bipolar Lead by an MRI body scan can cause injury.

Use caution when other MRI systems are used, since adverse events may occur because o different magnetic field distributions.

⚠ No scan in which the radiofrequency (RF) is transmitted by the body coil should be done on a patient who has the NCP System. Thus, protocols must not be used which utilize local coils that are RF-receive only, with RF-transmit performed by the body coil. Note that some RF head coils are receive only, and that most other local coils, such as knee and spinal coils, are also RF-receive only. **These coils must not be used in patients with the NCP System.**

⚠ **Therapeutic ultrasound.** Routine therapeutic ultrasound could damage the Pulse Generator and may be inadvertently concentrated by the device, causing harm to the patient.

⚠ **Extracorporeal shockwave lithotripsy** may damage the Pulse Generator. If therapeutic ultrasound therapy is required, avoid positioning the Pulse Generator part of the body in the water bath or in any other position that would expose it to ultrasound therapy. If that positioning cannot be avoided, program the Pulse Generator output to 0 mA for the treatment, and then after therapy, reprogram the Pulse Generator to the original parameters.

Diagnostic ultrasound is not expected to affect the NCP System.

⚠ The Pulse Generator may affect the operation of **other implanted devices**, such as cardiac pacemakers and implantable defibrillators. Possible effects include sensing problems and inappropriate Pulse Generator responses. If the Pulse Generator patient requires concurrent implantable pacemaker and/or defibrillator therapy, careful programming of each system is necessary to optimize the patient's benefit from each device.

ADVERSE EVENTS

Adverse events reported during clinical studies as statistically significant are listed in alphabetical order Ataxia (muscle movements or twitching, generally associated with stimulation); Dyspepsia (indigestion); Dyspnea (difficulty breathing, shortness of breath); Hypesthesia (impaired sense of touch); Increased coughing; Infection; Insomnia (inability to sleep); Laryngismus (throat, larynx spasms); Nausea; Pain; Paresthesia (prickling of the skin); Pharyngitis (inflammation of the pharynx throat); Voice alteration (hoarseness);Vomiting.

Other potential adverse events possibly associated with surgery or stimulation include but are no limited to the following:

Aspiration (fluid in the lungs); Blood clotting; Choking sensation; Damage to nerves or vasculature i the surgical area, including the carotid artery and jugular vein; Device (Generator and/or Lead) migration or extrusion; Dizziness; Dysphagia (difficulty swallowing); Duodenal ulcer, gastric ulcer; Ear pain; Facial flushing; Facial paralysis, paresis; Foreign body reaction to implants, including possible tumor formation; Formation of fibrous tissue, pockets of fluid; Heart rate and rhythm changes; Hiccuping; Incision site pain; Irritability; Laryngeal irritation (sore, painful throat); Left hemidiaphragm paralysis; Left recurrent laryngeal nerve injury; Left vocal cord paralysis; Low-grade fever; Muscle pain; Neck pain; Nerve injury; Painful or irregular stimulation; Skin, tissue reaction; Stomach discomfort; Tinnitus (ringing in the ears); Tooth pain; Unusual scarring at the incision site; Urinary retention; Vagus nerve paralysis; Weight change; Worsening of asthma and bronchitis; Worsening of cardiac abnormalities, including heart rate and rhythm.

⚠ Patients who manipulate the Pulse Generator and Bipolar Lead through the skin may damag or disconnect the Bipolar Lead from the Pulse Generator and/or possibly cause damage to th vagus nerve.

---

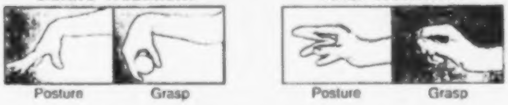
[1] The information contained in this Executive Summary for Physicians represents partial excerpts of important prescribing information taken from the *NCP Pulse Generator Physician's Manual*. The information is not intended to serve as a substitute for a complete and through understanding of the material presented in all of the Physician Manuals for the NCP System and its component parts nor does this information represent full disclosure of all pertinent information concerning the use of this product, potential safety complications, or efficacy outcomes.

FIRSTFlex™
improving reach, grasp and pinch together.

Caring For Life

FIRSTFlex™, for children with spastic hemiplegia, combines patented bracing with electrical stimulation.

Before Treatment
After Treatment



www.ultraflexsystems.com

Call 1-800-220-6670 for free video and research studies.

Circle #68 or visit www.eparent.com/adinfo

LINCOLN CENTER | for the Performing Arts

We bring the best of the performing arts to everyone

Photo: S. Be
Photo: J. Hon

Lincoln Center is proud to offer its Passport Program for children with disabilities.

Please call 212.875.5374 to find out about free weekend performances and our Meet-The-Artist School series.

Visit www.lincolncenter.org for accessibility information from Lincoln Center's Programs and Services for People with Disabilities.

Circle #49 or visit www.eparent.com/adinfo

EP

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

Editor-in-Chief	Rick Rader, MD
Medical Editor & VP of Medical Education	Fern R. Potvin
Senior editor	Kristen Georgi, MAT
Contributing editor	Natalie E. Gerber, PhD
Editorial/Marketing Intern	Christina E. Spatz
Editorial Intern	Megan Henninger
Information Systems Coordinator	Dennis Dusevic
Research Assistant	Susan Jenkins
Graphic Consultant	Dennis Wilkes
President, CEO & Publisher	Joseph M. Valenzano, Jr.
VP Business Development & Internet Projects	Vanessa B. Ira
VP Organization Relations & Consulting Editor	Bridget M. Lyne
Chief Financial Officer	Dolores A. Kinley
Ad Traffic Manager	Kendra Kelly
Sales Coordinator	Doris DeFina
Receptionist/Public Relations Coordinator	Robyn Sager
Art Direction, Design	Publishers Design Group, Inc. ✉annpdg@aol.com
Production Manager	Michael Longobardi
EP Library	Ron Richards (800) 535-1910 ✉eplibrary@aol.com
Webmaster	Ken Fleischer, Dynamic Media Works ✉webmaster@eparent.com

Jared F. Adams
EASTERN REGION:
(CT, ME, NH, NJ, NY, RI, VT)
✉jadams@eparent.com
(201) 489-4111,
Fax: (201) 489-0074

Barbara Nastro
SOUTHEAST REGION:
(AL, AR, DC, DE, GA, FL, MD, MS, NC, PA, SC, VA, WV)
SCHOOLS, CAMPS, RESIDENCES & CLASSIFIED
✉ nastro@blast.net
(908) 534-6366
Fax: (908) 534-6941

Annabelle and Gabe Jacobson
MIDWEST REGION:
(IA, IL, IN, KS, KY, MI, MN, MO, NE, ND, OH, OK, SD, TN, WI)
AUTOMOTIVE
The Lyon Group
✉ bellyon@megsinet.net
(847) 256-6850
Fax: (847) 256-6819

Larry Battistello
WESTERN REGION:
(AK, AZ, CA, CO, HI, ID, LA, MT, NM, NV, OR, TX, UT, WA, WY)
Marketing Plus
✉ seeme4ads@aol.com
(760) 320-8797
Fax: (760) 320-9728

Vanessa B. Ira
MASSACHUSETTS & INTERNET AD SALES
✉ viepmt@concentric.net
(201) 489-4111, ext. 209
Fax: (201) 489-0074

Color Separation/Film Preparation
Plate Masters Inc., Carlstadt, NJ 07072

Publishing & Editorial Office
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

Subscriber Service:
Exceptional Parent
P.O. Box 2078, Marion, OH 43306-2178.

Customer Service/New Orders:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

Exceptional Parent magazine was founded in 1971 by
Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 98

On Catching Myself Taking One Step To The Left

I changed my mind. I originally had planned to use this opening paragraph to suggest to the "exceptional parent" contingent of EP readers that they bypass this month's *Editor's Desk*. "Go on," I had planned to write, "just ignore this; it's intended for direct support professionals, teachers, therapists and physicians." It's not applicable to parents and it might only infuriate them. "Move on," I was going to write, "and we'll meet up at *Search & Respond*." But I changed my mind. The more I pondered the message I wanted to impart, the more I thought about the experience that prompted this editorial, the more I realized that parents also should read it. And I realized that parents would not only be able to relate to it but, by inviting them to read it, I was also acknowledging something that is often overlooked by professionals—the "humanness" of exceptional parents. Exceptional parents are, after all, simply human, not exceptionally human, not "Superparent". So now that I've brought you back into the fold, let me share with you something known only to one other person. Let me tell you how, two years ago, I caught myself "taking one step to the left."

I was in the men's room of the Morton J. Kent Habilitation Center in Chattanooga where, as most EP readers know, I'm the Director. The Kent Center serves as the think tank at Orange Grove, conjuring up innovative approaches to supporting people with complex biopsychosocial and developmental disabilities. While I washed my hands at the sink before leaving (as per the OSHA-required wall sign, not to mention validation of Koch's germ theory of 1879) I noticed a student in the mirror.

The Orange Grove student was sitting on the toilet with the cubicle door wide open. When I turned around to encourage him to close the door to provide himself with some privacy, I realized he'd had an "accident" and had soiled himself.

I looked around to see if he was accompanied by a classroom assistant and saw that he was alone. Perhaps the assistant is female, I thought, and is waiting outside for him. So I walked out, ready to alert her that she was needed. No one was in sight, so I surmised that the student had self- toileting skills and was on his own. I assumed he would return to the classroom, where his needs would be attended to and he would be changed. After all, I thought, those classroom teachers and assistants know their students better than anyone, and toileting is part of their routine and protocol. He'll be cleaned, powdered and changed within the next five minutes. I was confident in that as I walked toward the fountain in the center of the atrium of the Habilitation Center. Besides, the budget worksheets for next year were unfurled on my desk and I had to have them completed by the end of the day.

The fountain sits almost as an apex to a fork in the road. To the left of the fountain are the offices, conference and planning rooms of the Habilitation Center and to the right is the hallway leading to the classroom complex of the center's school division.

Preoccupied with figuring out how to stretch my conference and meeting resources for the upcoming year, I got closer to the fountain. With an almost-choreographed, fluid motion, my left foot announced to my body that I was going "left," back to my office and back to the budget. At that very instant, as dramatic as the governor calling in a stay of execution with two minutes to spare in some black and white classic movie, my right foot decided to overrule its counterpart. I found myself executing a full pivot, realigning myself. We weren't heading for my office; we were going back to the men's room. The engine room had gotten new coordinates from the bridge, and we were back on course, heading where I should have been going all along. Back to the men's room, to assure myself that the student was as tidy and clean as possible before he headed back to the classroom, where he would be welcomed as a pit crew would welcome a muddy sprint car and, as fast as possible, prepare him for another go at the track. What was I thinking? I thought. How did I ever get to where I took even one step toward the left? What mechanism kicked in to "right" myself? As I stood at the sink encouraging the student to wash his hands, I looked at the mirror and saw myself looking back.

Why had I left the bathroom in the first place? I could have come up with a compelling list of reasons, but I jettisoned them all and had a mini-celebration. The road not

taken (back to my office) was a dramatic near miss. I had somehow fixed on the wrong focus. My preoccupation with conjuring up innovative strategies to support people with special needs had almost caused me to lose sight of an obvious "innovative" opportunity right in front of me. My myopia, my priorities, my own press had, at least at that moment, led me astray. My fascination with robotics, Johns Hopkins, the Surgeon General, titanium, voice recognition software and periorbital activated environmental controls had almost allowed me to overlook the joy and sensibility of doing the right thing at the right time. A small thing, perhaps, but nothing was greater at that moment. I was reminded of an ancient Hebrew saying that reemerged during the Holocaust as commentary on the mass indifference: "If not me, then who? And if not now, when?"

The message here, I think, is for caregivers who are asked to perform the same duties repeatedly. It's for caregivers—including teachers, physicians, nurses, therapists, job coaches, house managers and DSPs—who find themselves doing what they do over and over again. Doing what they always do, especially without dramatic and vivid rewards, can sometimes seem fruitless, pointless, redundant and often inconsequential. It's not.

Exceptional parents, the parents that I originally thought should just skip over this editorial, are often more prone to feeling that these tasks are without end and without merit. Mainstream parents can at least appreciate that changing diapers is finite. Each change brings them closer to the eventual last time they will need to do it. Parents will often share the "memorable joy" of changing diapers with their kids on graduation from law school, or will embarrass them by telling all the details to their new daughters- or sons-in-law. Exceptional parents may never have the recollection of that memorable last time. And so, at times, even exceptional parents can find the tasks to be relentless, unceasing, daunting, unpleasant and monumental. Exceptional parents—like exceptional physicians, exceptional teachers and exceptional assistants—can find themselves taking a step toward the left. It's okay; it's human, it's universal and it's shared.

At the beginning of this editorial I said that I wanted to share this experience that was known only to one other person. Shortly after I took that one step to the left I shared it with my friend and colleague Hal Baker. Hal is the deputy director at Orange Grove and has a feeling for this field like few people I have ever met. He's seen it all and weathered the storms of "new age" wisdoms. "Rick," he said, "taking one step to the left on occasion is fine. It's the second, third and fourth steps that should earmark you for extinction."

Hal knows where we should be headed. I hope we all do. I hope it's to the right.

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

"THE VALUE OF OBSERVANT OBSERVATION" TO THE EDITOR:

I am a 30-year-old mother of three whose youngest child has severe CP as a result of perinatal asphyxia. I am also a pre-med student in biology at Towson University in Baltimore, Maryland. I was deeply touched by your insight in the Editor's Desk, "The Value of Observant Observation" (March 2002). You have touched on a subject that is often neglected—especially by academically focused students and residents. I don't know how many times my daughter could have been saved a lot of discomfort and aggravation if residents (as well as attending physicians, at times) had bothered to listen.

Often I find (especially with students and new doctors who have limited experience prescribing anything other than standard therapy) that parents are not even consulted when it comes to planning treatment. Why would anyone ever leave out a parent? How can one be an advocate when left out of the loop? I can think of many problems that could have been avoided had someone asked if we had previously tried a particular therapy. I don't know how many physicians came up with the "brilliant idea" to put my daughter on a particular medication to control her excessive secretions while she was an inpatient. If they had bothered to ask, I could have told them that even in the smallest doses this medication would cause her secretions to thicken, then she would go into respiratory distress. Often people get caught up in the physiology of things and neglect what is right in front of them.

I feel you have touched on a very important issue that needs to be shared, not only with the current medical student population, but with future medical students as well. I thank you for sharing your insight, and I only hope that more people begin to utilize their abilities to make common sense observations.

Natalie Blakeman

"NOTICEABLE DIFFERENCE"

To the Editor:

As an Infant Development Specialist who has been in the field (and often sitting on the floor with a baby) for many years, I have often thought about what you expressed so eloquently in your Editor's Desk ("On Noticing a Noticeable Difference," February 2002). I have had gut feelings and puzzled about whether there was something different/wrong/worrisome in a child or whether it was just his or her individual personality. Your article is so important that I shared it with a colleague at Harbor Regional Center here in the Los Angeles area because we had been concerned about one little toddler and had been speculating along these lines.

Linda S. Dingman, MA
Infant Development Specialist, CA

"GINA AND THE GROUP HOME"

To the Editor:

The article "Gina and the Group Home" (March 2002) should have been entitled "Gina and Her Family's Group Home." The article was disheartening and I hope it doesn't become the trend. It was filled with self-pity and a lot of "what about me" which inevitably became the attitude of the siblings as well. It's a matter of attitude and perspective; is the glass half empty or half full?

To pretend that Gina has not missed her family is a disservice to all children with disabilities. For the special children in our lives, it is not always something we can see but something they can feel. It might be something as simple as the scent of your mother as she bends down to kiss you good night or the way she strokes your hair as you fall asleep. You feel but you cannot respond.

Gina would have still signed, would have still grown and improved. There was no magic in the group home or in the absence of her family. The magic was in the interventions and attitudes of those around her. I also would like to point out that the caregivers at the home will never be consistent; as employees, they will come and go. Gina will never know consistency again. Gina's family had an opportunity to grow as a family, to become unique in their roles as mother, father and sisters.

I am the mother of five children, four girls and a boy. Kevin, our youngest, has global developmental delays and autistic tendencies. Our hands are full, believe me, but not how you may be thinking right now. Our hands are full of love, patience and hope for the future. I wish only the best for families who are facing times of despair. It's too bad this family in crisis could not have been helped instead of being separated. With a renewed attitude and renewed spirit, this family could be together again. That's my hope for Gina and her family.

Deirdre Finnegan Shea
Worcester, MA

To the Editor:

I finally got around to reading the March 2002 issue. The article by Phyllis Donovan titled "Gina and the Group Home" really touched me. My son is 9 1/2 years old, severely mentally disabled (he has tuberous sclerosis), totally lovable, has autistic characteristics and is nonverbal. So the article really hit home.

I saw at the end of the article that the Donovans live in the New York metropolitan area. I'd like to learn more about (this group home), for the future, for my son.

Anne Campbell, NY

We encourage letters on any subject. Send them to: EP Magazine, Attn: Letter to the Editor, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com. Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified by full name and state. Please include your phone number and/or e-mail address on all correspondence.

no more
frustration -
just fun

LECKEY®

Advance Bath Chair

New Design

The most extensive height range and adjustable seat angles make bath positioning easy.

Extra-soft mesh material and padded support bars give your child a more comfortable and enjoyable bath time.

Take the Advance Bath Chair from the tub to the shower with the optional trolley

Also available is the Basic Bath Support that provides adjustable positioning angles at a fixed height.

And The FUN Doesn't Stop There

Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Call us today for more information.

- *Lighter mobile bases*
- *More adjustable components*
- *Peer level positioning*
- *Child friendly positioning straps*
- *Playful colors*

Pronestander

Freestander

Totstander

Toilet/Shower Chair

Easy Seat

SAMMONS® PRESTON
AbilityOne

Leckey® products are brought to you exclusively by Sammons Preston®

Start the fun today! Contact your local Sammons Preston distributor or home health dealer for more information.

Or call Sammons Preston at
1-800-323-5547

Circle #60 or visit www.eparent.com/adinfo

HARD MANUFACTURING

AGE APPROPRIATE

BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

The Stockton features full crib safety sides

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #43 or visit www.eparent.com/adinfo

EP
has the
information an
"Exceptional
Parent"
like you
needs

EP
Exceptional Parent

Your paid subscription
includes the
EXCEPTIONAL PARENT
2003
Annual
Resource
Guide,
which
normally sells
nationally for $19.95.

This invaluable reference tool is a "must-have" for exceptional parents

Save $5.00
by ordering on-line at:
www.eparent.com
For telephone orders call:
877-372-7368

Circle #199

Subscribe and be part of a network of "Exceptional Parents"

EP

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: **www.eparent.com**

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______ Exp. Date ______
Name ______
Address ______
City ______ State ______ Zip ______
E-mail ______ Yes, I want more information to help me everyday.
Signature ______ E-mail ______

BJUN2

Subscribe and be part of a network of "Exceptional Parents"

EP

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: **www.eparent.com**

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______ Exp. Date ______
Name ______
Address ______
City ______ State ______ Zip ______
E-mail ______ Yes, I want more information to help me everyday.
Signature ______ E-mail ______

BJUN2

Make someone a part of a network of "Exceptional Parents"

EP

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95
☐ 2 Years (24 issues) $65.95
☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year.
Other foreign countries $57.95 per year.

661

Save more money: Order off the Web: **www.eparent.com**

PLEASE SEND MY GIFT OF EP TO:
Name ______
Address ______
City ______
State ______ Zip ______

THIS GIFT IS FROM:
Name ______
Address ______
City ______
State ______ Zip ______
☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______
Exp. Date ______
Signature ______

XJUN2

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

Exceptional
Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer life for themselves and for their children.

Exceptional
Parent's MISSION

IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

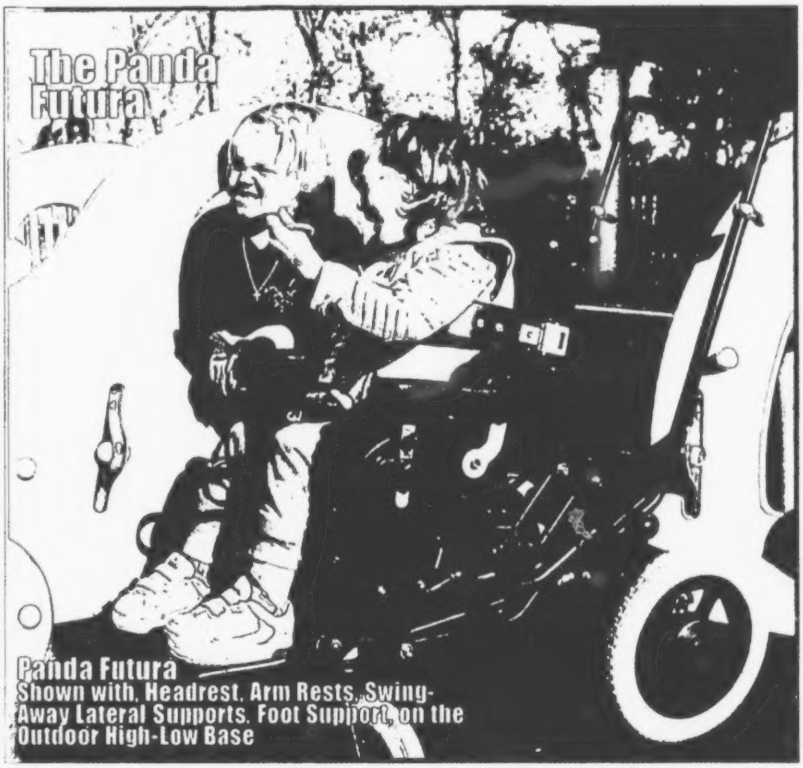
SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional
Parent

www.eparent.com

Informed Parents

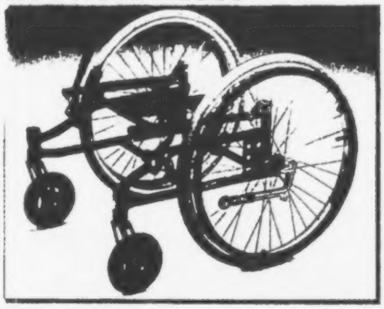
Where Parents Keep Up To Date On Products For Their Children's Special Needs



Panda Futura
Shown with, Headrest, Arm Rests, Swing-Away Lateral Supports, Foot Support, on the Outdoor High-Low Base

Our Panda chair is one of our most versatile seating systems. With its adjustable seat, wide variety of options, and different frames, the Panda Futura can solve almost every seating situation your child may face.

Wheelchair Base



Our Different bases allow you and your child to do more and be more places. The Wheelchair Frame (Left) is the perfect option for the active child who likes to explore their surroundings.

The Tiger Stroller frame (Right) folds easily for transport and storage. It is a great option for family walks.

Our High-Low Frames allow your child to "be where the action is", by adjusting from floor height for interaction with peers, or at desk height for any home or school activity. The Outdoor Frame (Above) offers rugged wheels for all terrains, while our Indoor Frame (Lower Left) is smaller and easy to manuver around the home or classroom.

Indoor High-Low Base

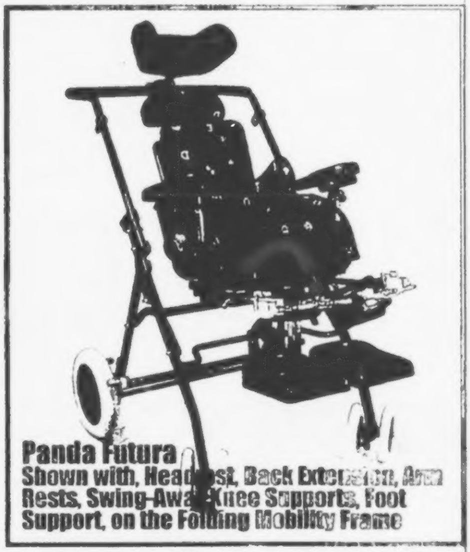
Desk Height

Floor Height

PANDA FUTURA

Fun Fact

The Panda Futura can be easily transferred to any of our Mobile bases.



Panda Futura
Shown with, Headrest, Back Extension, Arm Rests, Swing-Away Knee Supports, Foot Support, on the Folding Mobility Frame

Information/Free Catalog CD Rom
1-800-336-7684
snugseat.com

SNUG SEAT®

BEST COPY AVAILABLE

Circle #62 or visit www.eparent.com/adinfo

Search & Respond

S

Spinal fusion surgery

My 15-year-old daughter does not seem uncomfortable now, but doctors tell us that without spinal fusion surgery she will eventually be unable to be in a sitting position. My daughter uses a wheelchair, is not able to speak, and has chronic digestive discomfort. Her response to the discomfort is to rock violently in her chair.

I worry that she'll have pain after surgery due to problems with hardware because she is so active. We limit her diet and are able to keep her comfortable and happy most of the time, but still the violent rocking is very common for her. She also loves to spend time on the floor: she rolls, pivots, and spends hours propped on her elbows playing with tape player (loves music).

Has anyone in this position refused surgery and found that the worst didn't happen as doctors warned? I want to do what's best for her, but have such fear of taking away her joys and giving her discomfort. Information about positive experiences with the surgery would be helpful, too.

—459, via EP Web site

Dr. Feudtner: Whenever considering how to care for a child with special needs, it can be very useful to ask: what are we trying to accomplish? For your daughter, you have an immediate concern (her digestive discomfort) and a more distant concern (potential future discomfort when sitting due to progression of her scoliosis). To address her apparent gastroesophegeal reflux disease (heart burn), is she already on a proton-pump inhibitor, like omeprazole? She really should be, as these medications have been shown to improve the quality of life for children with significant heart burn. Regarding the scoliosis surgery, you should feel comfortable asking your doctors the following questions: Why should we do this surgery now, and not in a few years? (Usually, the answer is because they can only reduce the curve in the spine by about half, so letting it progress further will ultimately mean a larger permanent curve.) What are the potential benefits of the surgery? (More comfortable sitting and easier breathing?) What are the risks? (As with any surgery, there are several important ones that you need to discuss openly with your doctors.)

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our Web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Filling a cavity may be difficult

My 20-year-old son, Steven, who has mental retardation, has a dental cavity for the first time in his life. The pediatric dentist who was wonderful with him retired a few months ago. The dentist who took over the practice is unable to even clean Steven's teeth, let alone think about filling a cavity. He has proposed setting Steven up for intravenous anesthesia just so he can fill the cavity, although he's never done this before. Steven is on medication for minor seizures, but the dentist has assured me that the anesthesia should not be a problem and that since it should take effect within a minute, keeping the needle in his arm would not be difficult.

I would like to know how other parents have dealt with dental care for their children, especially in a case like this where drilling has to be done.

—210 via EP Web site

Respond

R

GT Difficulty

SH (Feb. 2002) has a grandchild with a gastrostomy tube (GT) which needs continuous venting and which gets in his way and also bleeds at the site of insertion.

Our son, Andrew, has a Ross Stomate™ Low-Profile Tube (http://www.ross.com (800) 258-7677), which has been wonderful! It doesn't need to be vented. It is only changed about once every two to three years. It is made out of heavy duty plastic, it looks like a little Chinese lantern, and it is installed by a doctor with a special little instrument. It has allowed Andrew to learn to burp on his own. It is flush to the skin, so he can roll all over the place without harming himself or the g-tube.

—JP, via e-mail

My daughter also had a long g-tube which dangled and frequently was "in the way." I used the webbing used for casts. It is actually a cloth "tube" which is webbed and placed on the child's skin before the casting occurs. I received it from the hospital when she had her g-tube placed. I cut a 5-6 inch length and placed it on her under her shirt. I then folded it up making a "pocket." Inside the pocket I placed the long g-tube. It was always out of the way, it wasn't too confining as it was webbed in design. I washed it out every few nights. You should be able to find this through a home health store or hospital equipment supply place. You could buy a large, sleeveless undershirt and fold up the bottom and place the g-tube in the "pocket." The undershirt may need to then be pinned up as it isn't as stretchy as the web material I described. Good luck.

—KF, via EP Web site

Instant S&R

S **Touching feces**

My 5-year-old daughter has cerebral palsy. She operates at the developmental level of a 6- to 9-month-old. She has a g-tube, is non-verbal, cannot sit up without support and cannot walk. Our problem is when she has a bowel movement, she gets her hands into it. She will put her hand down the waistband of her clothes to access the diaper or if she has on a one piece outfit, she will reach up through the pants leg. She doesn't play in it or seem to enjoy doing this, but appears to do this because she doesn't want a dirty diaper on. She used to wiggle her hips back and forth so we would know she needed her diaper changed. She has stopped this "dirty diaper dancing" and has moved on to this new method to attract attention to her dilemma. We would love to hear any and all suggestions to resolve this issue.

—BE, 345, via EP web site

R My son is now 16 years old and had been doing that for years. We stopped him from doing it seven years ago by putting "bodysuits" on him. This way he can not get into his diaper from the top. He wears long pants that are very light weight but tight at the bottom and almost like girl's leggings. No one ever knows that they are girl's because they are solid colors. We buy the bodysuits from Newport News (http://www.newport-news.com, (800) 688-2830). They have no sleeves and a round neck so they won't show under clothing. Try it—she may stop doing this when she realizes she can't get into the diaper anymore.

—536, via EP Web site

Hyperbaric Oxygen Therapy [HBOT] is the breathing of 100% oxygen under increased atmospheric pressure. The effects of HBOT on the organs and tissues of the body are multi faceted.*

South Florida Center for H.O.P.E. offers a clean and bright friendly atmosphere, using only state-of-the-art equipment. Our doctors and technicians are trained by a UHMS accredited course and certified in HBOT by the NBDHMT. They come with many years experience in the field of hyperbaric medicine.

* Hyperbaric Medicine Practice
Eric P. Kindwall, M.D.

WE OFFER H.O.P.E.
[HYPERBARIC OXYGEN PRODUCING ENVIRONMENT]

CONDITIONS TREATED WITH HBOT
- CEREBRAL PALSY [CP]
- TRAUMATIC BRAIN INJURY
- ANOXIC ISCHEMIC ENCEPHALOPATHY (AIE)
- NEAR DROWNING
- STROKE [CVA]
- MULTIPLE SCLEROSIS [MS]
- NON-HEALING WOUNDS*
- RADIATION INJURY*
- AUTISM

* CURRENTLY APPROVED BY FDA

ANCILLARY SERVICES
- INTEGRATED MANUAL THERAPY
- PHYSICAL THERAPY
- OCCUPATIONAL THERAPY
- SPEECH THERAPY
- BIO RESONANCE THERAPY
- NEURO-BIOFEEDBACK

Dr. Ross Clark, M.D. Medical Director

South Florida Center for H.O.P.E
1898 H West Hillsboro Blvd.
Deerfield Beach, FL 33442
[954] 571-9392 Toll Free: [866] 473-HOPE

EP neither endorses nor denies the effectiveness of hyperbaric oxygen therapy. For Editor-in-Chief statement see our Contents page.

Circle #63 or visit www.eparent.com/adinfo

The BEST strollers in the WORLD!
by Baby Jogger

Our Special Needs strollers are lightweight, easy to fold, and a joy to push...

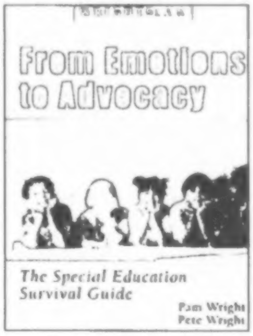
© BABY JOGGER
www.babyjogger.com • (509) 457-0925

Circle #65 or visit www.eparent.com/adinfo

665

book notes

by Joy Liebeskind


From Emotions to Advocacy
The Special Education Survival Guide
Pam Wright
Pete Wright

Wrightslaw: From Emotions to Advocacy
The Special Education Survival Guide
by Pam Wright
& Pete Wright
Harbor Law Press
Available through the EP Library; (800) 535-1910
web site: http://www.eplibrary.com
Item code: HP0088SE
Price: $29.95 plus shipping

Did you promise yourself you would be better prepared for your Individual Education Plan (IEP) meeting this year? If so, *Wrightslaw: From Emotions to Advocacy-The Special Education Survival Guide* can serve as your guide, whether you are new to IEPs or a seasoned pro. All the information you will find in this book is presented in a clear and concise format. You will not want to skip a single page your first time through the book, from the section on building you up to be your child's best advocate, to the glossaries of terms. This is the book you will pull out before every meeting, and take with you to most.

Planning for the future is hard to think about, but it is the driving force behind the goals to be written at your IEP meeting. The book outlines a "Master Plan." This process is broken down step-by-step for you with numerous samples as well as other references to assist you. A good master plan includes short- and long-term goals, as well as academic and non-academic goals.

And who will keep all the players focused on your child's master plan? You the parent, of course! Learn all the skills you need to do this well, as you progress through the early chapters. Terms, choices, how the system works, and alternatives are all explained in detail. What to watch out for, how to handle conflicts, complaints and personalities are all covered. You will learn to spot a problem before it becomes a major one with advice you can use again and again.

Problem solving options are presented in every section. You are taught how to manage crisis for the short- and long-term. There will be many times when you will find yourself referring to this section of the book before you react as your child grows.

Tests and evaluations are always something of a mystery to parents. Learn how to evaluate which tests are appropriate and how to use the results in your master plan. Charts and graphs are used to explain test scores so they become meaningful to you. This information will help you in making sure goals are measurable and in evaluating whether a child is truly progressing. The book even gives parents a "homework assignment" which allows them to analyze tests their child has taken in the past. I found the test information to be invaluable in helping me be a strong team member and advocate.

Information on how to organize and store all the "paper work" is also included here. What do you need to keep? How can you organize it so it is meaningful and so you can reference it when it is needed?

With all this new knowledge at your fingertips you are now ready to think about this year's IEP meeting. The Wrights begin by presenting "SMART IEPs." You will look at goals, objectives and benchmarks in a new way. Progress is discussed in terms of how it can be measured and how parents will be kept informed.

Many real examples of children's goals are given. You will have learned so much that it will be easy to see how to improve your current plan. At this point you may want to rewrite your existing IEP even if it isn't time for it to expire.

You will also find a whole section on the law. You may want to bring your copy of this book with you to meetings so that if something is quoted as not being allowed by law, you can check it out on the spot. An informed parent makes a better advocate.

The next section of the book is on "creating a paper trail." The information and tips here are valuable in all conflict situations. Sample forms are used, along with lists of what needs to be included in letters. Whether you need to verify something that was said or clarify your own position, you want to be sure you include everything that is needed. You will use all this information over and over, especially the tips about how to deliver letters to school. You won't want to skip this section!

Parent meetings are negotiations, and you are now ready for the section on how to negotiate while building a strong family-school relationship. While it is natural to be stressed over these meetings, strategies are given to keep things moving smoothly. With all your new skills and confidence your child is sure to come out with a much better program for the future!

Joy Libeskind is director of the Connecticut Parents Resource Library and co-chair of the Greater Waterbury Local Interagency Coordinating Council.

Clay, Danny, Robin and Danielle Wagner live in Fort Lauderdale, Florida. Clay is autistic and has a seizure disorder.

"We're a PediaSure® Family."

"PediaSure helps us give Clay the nutrition he needs."

All kids need proper nutrition for growth and development. If your child is not getting enough of the right nutrition from regular food or has special feeding needs, ask your doctor about the complete, balanced nutrition of PediaSure. It's specially formulated to provide children with proper amounts of protein, fat, carbohydrate, vitamins and minerals. Available in your local supermarket, drug or discount store.

PediaSure
Pediatrician Recommended
Lactose Free

Available through WIC®*

*If your child has special dietary needs, check with your physician or local WIC clinic to see if your child is eligible to receive PediaSure through the WIC program. WIC is a registered trademark of the U.S. Dept. of Agriculture.

© 2001 Abbott Laboratories

Circle #59 or visit www.eparent.com/adinfo

On The Road To Orlando

WORLD CONGRESS & EXPOSITION ON DISABILITIES

OCTOBER 3 - 5, 2002

ORANGE COUNTY CONVENTION CENTER
ORLANDO, FLORIDA

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD
WCD
BUST!

EDUCATIONAL SPONS

- Allergan, Inc.
- American Academy for Cerebral Palsy & Developmental Medicine (AACPDM)
- American Academy of Pediatrics
- American Association for Active Lifestyles & Fitness (AAALF)
- Association of University Centers on Disabilities
- Child Neurology Society

MEDIA SPONSORS

- Active Living magazine
- Disabled Dealer of Southeast
- EP (Exceptional Parent)
- inMotion
- New Mobility
- PALAESTRA
- Teaching Exceptional Children
- Today's Caregiver
- We Media

Employment Symposium
hosted by
Florida Division of Vocational Rehabilitation Services

SUPPORTING ORGANIZATIONS

- AAMR
- America's Athletes with Disabilities
- Amputee Coalition of America
- Autism Society of Florida
- Council for Exceptional Children
- Easter Seals
- Families of S.M.A.
- Family C.A.F.E.
- Family Voices
- Florida Alliance for Assistive Service and Technology, Inc. (FAAST)
- Florida Children's Forum/Central Directory
- Florida Institute for Family Involvement (FIFI)
- Muscular Dystrophy Family Foundation
- National Family Caregivers Association
- National Multiple Sclerosis Society
- National Perinatal Association
- RESPECT of Florida
- Southeast Disability & Business Technical Assistance Center
- Special Olympics
- Spina Bifida Association of America
- TASH
- UCP
- United Parents' Syndicate on Disabilities

1068

(877) 923-3976 x832 ◆ wcdinfo@wcdexpo.com ◆ www.wcdexpo.com

Circle #72 or visit www.eparent.com/adinfo

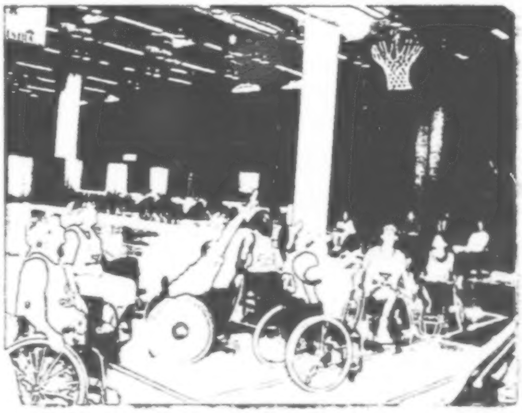
Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—October 3 - 5, 2002
LOCATION:
Orange County Convention Center—Orlando, Florida

A UNIQUE GATHERING— A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract **physicians • families • direct support professionals • people with disabilities • allied health care professionals • educators • adapted physical education specialists.**



TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.

SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more.

EMPLOYMENT SYMPOSIUM PAVILION: Human resource managers will discuss career opportunities.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.

CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment.

- All WCD attendees can experience discussions by internationally renowned experts specializing in neurology, orthopedics, pediatrics, internal medicine, family medicine, physical medicine, epidemiology, DDS, movement disorders, mitochondrial and metabolic disorders, neonatology, seizure disorders, autism, and other disabilities and chronic conditions as well as general practitioners.
- CME and CEU accreditation will be provided through approved accreditation institutions.
- Hear parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.
- An Employment Symposium produced in conjunction with the Florida Department of Education, Division of Vocational Rehabilitation Services will offer sessions for people with disabilities, their families and employers.
- Learn from special education professionals what is going on in classroom environments.
- Participate in adapted physical education activities and seminars.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

SHOW PRODUCER: HAB H.A. BRUNO, LLC
IN ASSOCIATION WITH: EP Exceptional Parent
GOLD SPONSOR: sigma-tau PHARMACEUTICALS, INC.
CONFERENCE SPONSOR: EP Foundation for Education, Inc.

WCD'S SPECIAL FEATURES

The World Congress & Exposition on Disabilities (WCD) will offer many special features at this year's event in Orlando, Florida on October 3-5, 2002. Our move to Florida brings about many exciting developments including the addition of an **Employment Symposium and Pavilion**. Sponsored by the Florida Division of Vocational Rehabilitation Services (VRS), a 50 session symposium has been planned to provide participants, individuals with disabilities, VRS staff, employers, and others with an opportunity to engage in various employment focused discussion sessions. The mission of the VRS is employment and increased independence for people with disabilities. They provide services to eligible persons with physical or mental disabilities who seek to prepare for, secure, regain, or retain employment. Anyone may apply for services. The physical or mental impairment must constitute or result in a substantial impediment to employment. The individual's employment outcome must benefit from VRS. The individual must require VRS to prepare for, to obtain, to retain or to regain employment.

The Employment Pavilion, sponsored by McDonald's Corporation, will include human resource managers from dozens of companies including local and national corporations and government agencies for the purpose of discussing hiring opportunities for those seeking employment.

Another Florida connection will produce our **Assistive Technology Pavilion**. The Florida Alliance for Assistive Services and Technology, Inc., (FAAST) is a non-profit organization responsible to provide consumers of assistive services and technology with awareness, access and advocacy for the variety of assistive technology available in the world today. They are a membership organization that helps individuals with disabilities acquire assistive technology and achieve their goals in school, work and recreation. FAAST assists individuals when working with Education, Vocational Rehabilitation, Developmental Services and other organizations and agencies.

At the Assistive Technology Pavilion, you will be able to see demonstrations, participate in hands-on applications, and ask questions about the latest in assistive technology. The pavilion will include special keyboards, pointing devices and accessible computer software that will allow you to work on the computer. There will be furniture on display that will adjust to your needs in a wheelchair or a specialized office chair. The WCD and FAAST hope that you will experience success and productivity using equipment that is readily available. Stop by and try it out.

In addition to work-related equipment, FAAST will also display assistive technology for independent living. They will have many different products for activities of daily living, personal care, grooming, eating and food preparation. FAAST has assistive technology for improving the quality of your life, from working to living as independently as possible.

Last but not least, America's Athletes with Disabilities (AAD) is proud to host the **Sports and Recreation Activity Center** at this year's WCD. America's Athletes with Disabilities is a national organization with the mission to promote and sponsor sports, recreation, leisure, health and fitness events for children and adults with disabilities. More than 100 disability sports events occur each year under the banner of the *Victory Games*.

The Activity Center will feature on-site individual and team competitions, demonstrations and training by elite athletes and opportunities to try-out different sports and sports equipment. Physical fitness and recreational activities for those with more severe disabilities will be included in this year's programming. Visits and autograph sessions with celebrity sports stars are also planned.

The Sports Activity Center, hosted by AAD will be the home for several participating disabled sports organizations and teams from throughout the USA. A visit to the Activity Center can introduce you to the sport and provide you with the opportunities and contacts that you need to join the game back home.

Further to the special features, this year's WCD will offer a conference program of over 150 comprehensive sessions, sponsored by the EP Foundation for Education, Inc., designed to educate many disciplines within the disability community. Attendees will also have an opportunity to examine a wide array of the latest products and services from more than 250 exhibitors representing pharmaceutical, assistive technology, automotive, mobility, durable medical equipment, personal care, insurance, computer, nutrition and many other industries.

EXHIBITORS

AAMR
Accessibility Services, Inc.
A.C.E. Environmental
Acorn Stairlifts Inc.
Active Living Magazine
Advanced Respiratory
Advantage Vans of Central Florida
Allergan, Inc.
American Academy for Cerebral Palsy & Developmental Medicine (AACPDM)
American Association for Active Lifestyles & Fitness (AAALF)
America's Athletes with Disabilities
Amputee Coalition of America
Anew International
Angelman Syndrome Foundation
Anne Carlsen Center for Children
Aquatic Access Inc.
Aurora Ministries
Autism Society of Florida
Barrier Free Lifts
Best Bath Systems
Beyond Adversity TV
Bodypoint Designs Inc.
Body Sense
Bunni-Steps Design
Cambrooke Foods
Canine Companions for Independence
Challenge Publications
Child Neurology Society
Cloister Creek
Columbia Medical
Communication Access Network
Communicating Partners Center
Concord
Continental Press/ Seeding Publication
Convaid Inc.
Council for Exceptional Children
Crotched Mountain
David Mandt & Associates
DBH Attachments Inc.
Defense Threat Reduction Agency
Department of Veterans Affairs
Department of Defense Dependents Schools
Dietary Specialties
Disabled Dealer Magazine
Dolphin Human Therapy
Downi Creations, Inc.
Driving Aids Development Corp.
Dystonia Medical Research Foundation
Easter Seals
Economic Mobility
El Dorado
Emergency Caller Systems/Peat
English Avenue Industries
EP (Exceptional Parent)
EP Foundation for Education, Inc.
Epilepsy Foundation
Families of S.M.A.
Family Voices
Federal Medicare Agency
Flaghouse Inc.
Florida ADA Leadership Network
Florida Alliance for Assistive Service and Technology, Inc. (FAAST)
Florida Children's Forum/Central Directory
Florida Independent Living Council
Florida Institute for Family Involvement (FIFI)
Florida Spinal Cord Injury Resource Center
Ford Mobility Motoring Program
Freedom Concepts
Gabby's
Guldmann Inc.
HealthSouth
Heartspring School
Hewlett Packard
Hoveround Corp.
inMotion Magazine
Invacare
International Broadcasting Bureau
Island Dolphin care, Inc.
JayJo Books
Judge Rotenberg Educational Center
KayJae Manufacturing Co., Inc.
Learning Strategies, Inc.
Magitek.com, LLC
McDonald's Corporation
Merrill Lynch & Co., Inc.
Metroplex Voice Computing Inc.
Mind Wing Concepts, Inc.
Muscular Dystrophy Family Foundation
MyMedMart, Inc.
National Disability Sports Alliance
National Family Caregivers Association
National Institutes of Health
National Multiple Sclerosis Society
National Perinatal Association
Newhope Generation
New Mobility Magazine
NISH
Ocean Hyperbaric Center
Oxy-Health Corporation
PALAESTRA
Pathways Development Group, Inc.
Perkin Elmer Life Sciences
Possibilities Foundation, Inc.
Prentke Romich Company
Pride Mobility Products Corp.
Rare Disease Therapeutics
Remedia Publications
RESPECT of Florida
Ricon
Rifton Equipment
Ross Laboratories
Sammons Preston
Scooter Lift Mfg Co.
Search Beyond Adventures
Shire US Inc.
SHS NORTH AMERICA
Sigma Tau Pharmaceuticals, Inc.
Social Security Administration Office of Disability
SourceAbility
Southeast Disability and Business Technical Assistance Center
Southpaw Enterprises, Inc.
Special Olympics
Spina Bifida Association of America
Sunrise Medical
Super Duper Publications
SureHands Lift & Care Systems
TASH
Teaching Exceptional Children
The Autism Recovery Foundation
The Center for Discovery
The Disability Resource
The Hali Project
The Liberty Motor Co.
The National Neurofibromatosis Foundation, Inc.
Theradapt
Today's Caregiver Magazine
UCP (United Cerebral Palsy)
United Parents' Syndicate on Disabilities
U.S. Customs Service
U.S. Department of Justice
U.S. Disabled Athletes Fund
Vail Products, Inc.
Vision For Life
Volkswagen of America
WALMART
We Media
WE MOVE
Wheelchair Getaways

Exhibitors at press time

Please send me information on the World Congress & Exposition on Disabilities, October 3-5, 2002

AM INTERESTED IN: ☐ Exhibiting at the Show ☐ Attending the Show

lame

ompany

ddress

ity State Zip Code

elephone Fax

mail

Send Me Information:
877-923-3976, x832
Fax this page to:
201-226-1236
Mail this page back to:
WCD
210 Route 4 East
Suite 403
Paramus, NJ 07652
Email your request from:
www.wcdexpo.com

For complete details, visit our website at www.wcdexpo.com, or call: (877) 923-3976 • (201) 226-1446

EP6/02

WORKING TOGETHER: Computer Technology and People with Mobility & Sensory Impairments

by Sheryl Burgstahler, PhD, and Dan Comden

People with disabilities meet all types of barriers to their independence. However, technology is helping to lower many of these barriers. Computing technology for tasks such as reading, writing, communicating and searching for information on the Internet is helping many people with disabilities gain greater independence.

HOW CAN TECHNOLOGY HELP?

While it is helpful to recognize the specific limitations of an individual, it is more important to focus on the task to be completed and how his abilities, perhaps assisted with technology, can be used to accomplish the goal or task. Specific accommodations can then be explored that provide access to software or to a specific device such as a keyboard or mouse.

This list is not exhaustive; people with disabilities, parents, teachers and adaptive technology practitioners should consider other approaches as well. New hardware and software is constantly under development and promises to continually improve access options. Additionally, many successful accommodations have been made using homemade or other low-tech materials. Following are descriptions of some computing tools that have been used effectively by individuals with disabilities.

MOBILITY IMPAIRMENTS

The specific impact of a mobility impairment and the resulting need for adaptive technology are unique to each individual. The impact of a disability may be mild or severe in how it affects an individual's ability to access a computer.

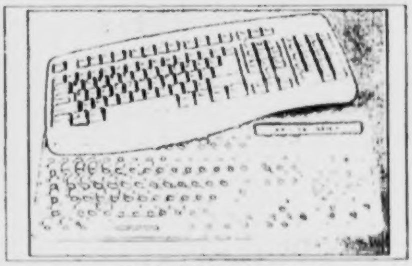
Keyboard Access

The keyboard can be the biggest obstacle to computing for a person with a mobility impairment. Fortunately, those who lack the dexterity or range of motion necessary to operate a standard keyboard have a wide range of options from which to choose. Pointers can be held in the mouth or mounted to a hat or other headgear and used to press keys on a standard keyboard. Repositioning the keyboard to the floor can allow someone to use his feet instead of his hands for typing.

Kensington's Trackball

Before purchasing a complex keyboard option, it is a good idea to evaluate the accessibility features that are built-in on current popular operating systems. For instance, the Accessibility Options control panel in current versions of Microsoft Windows™ contains a variety of settings that can make a standard keyboard easier to use:

- For a person who has a single point of entry (a single finger or mouth-stick), use of StickyKeys allows keystrokes that are usually entered simultaneously, such as Ctrl-key shortcuts found in menus, to be entered sequentially.
- FilterKeys can eliminate repeated keystrokes for a person who tends to keep a key pressed down too long. Check the Settings menu for these features and experiment with different time delays for optimum effect. The Macintosh operating systems have similar features in the Easy Access control panel.
- Consider using the features common in popular word processor programs, such as Microsoft Word™, to ease text entry. The AutoCorrect™



TechAble Keyguard

feature of Word allows sentences or blocks of text, such as an address, to be represented by unique and brief letter sequences. For example, entering "myaddr" could be set to automatically display one's address in proper format. Long words can be abbreviated and entered into the AutoCorrect settings to increase typing speed and accuracy.

Keyguards

A keyguard is a plastic or metal shield that fits over a standard keyboard. Holes are drilled into the guard to help an individual with poor dexterity or hand control press only the desired key without inadvertently pressing other keys. Keyguards are available from a variety of manufacturers (e.g., Don Johnston, TechAble).

Alternative keyboards

Alternative keyboards can be considered for a person who cannot effectively operate a regular keyboard. Keyboards can be smaller (e.g. Tash's MiniKeyboard™) for people who have limited range of motion, or larger for a person has good range of motion and poor dexterity. Several vendors offer an array of alternative keyboards to accommodate a variety of limitations (e.g., Infogrip).

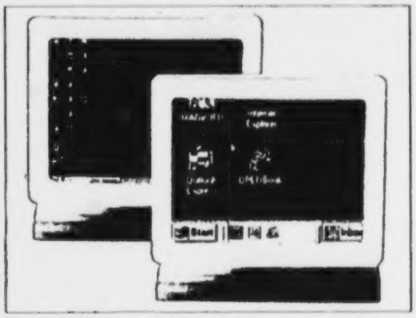
If physically activating a keyboard—whether through changing the settings or switching to an alternative keyboard—is not possible, think about a virtual keyboard. A virtual keyboard appears on the computer screen as a picture of a keyboard. A mouse, trackball or alternative pointing system activates the keys on the screen and inserts the appropriate keystrokes into the desired program. A person can enter text by clicking on specific keys on the keyboard image. Modifier keys such as Ctrl and Alt can also be accessed, as can the function keys. Some virtual keyboards incorporate word prediction (see below) to increase entry speed and may include alternate layouts in addition to the traditional "QWERTY" layout found on standard keyboards.

Word Prediction

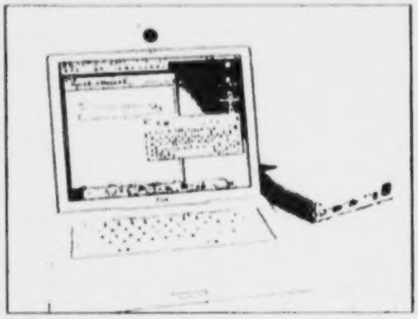
Typing words correctly and quickly can be a challenge for some people with mobility impairments. Word prediction programs prompt the user with a list of likely word choices based upon words previously typed. Some word prediction software automatically collects new words as they are used, and consider a person's common vocabulary when predicting in the future. Word prediction is often used with a virtual keyboard to increase accuracy and typing speed.

Alternative Pointing Systems

With the advent of graphically-oriented operating systems, it is vital to have access to a mouse or an alternative pointing device. For those who lack the coordination to use a standard mouse, there are many alternatives to consider. Trackballs are a good first choice; the control surface can be easier to manipulate and the buttons can be activated without affecting the pointer position. Some trackballs (e.g., Kensington) offer additional buttons that add functionality such as double-clicking, click and hold, and other commands, and can be programmed to a person's specific needs.



Freedom Scientific's MAGic™ Software



The HeadMouse™ mounted
on an Apple iBook™

Other alternative pointers can be found in many mainstream computer stores and supply catalogs. External touchpads, similar to those built into many notebook computers, offer an ideal pointing system for some. Handheld pointing devices such as the ProPoint™ (Interlink Electronics) with a small control surface area may be useful for someone with very limited hand mobility. For people with mobility impairments who already use a joystick to drive a wheelchair, a device such as the Roller Joystick™ (Penny & Giles) may be an excellent choice.

A person with good head control who cannot control a mouse or alternative pointing device with any limb should consider using a head-controlled pointing system such as HeadMouse™ (Origin Instruments) or HeadMaster™ (Prentke Romich). These head-controlled pointing systems use infrared detection and a transmitter or reflector that is worn on the user's head and translates head movements into mouse pointer movement on the computer screen. Use of

continued on page 32

WORKING TOGETHER: COMPUTERS

RESOURCES

Ai Squared
P.O. Box 669,
Manchester Center, VT
05255
Phone: (802) 362-3612,
Website:
http://www.aisquared.com

Alva Access Group
436 14th Street
Suite 700
Oakland CA 94612
Phone: (888)318-ALVA
(2582)
Website:
http://www.aagi.com

Arkenstone
Freedom Scientific's
Learning Systems Group
480 California Avenue
Suite 201
Palo Alto, CA 94306-1609
Phone: (888) 223-3344
(650) 475-5435
(Formerly known as Arkenstone, the association is now part of Freedom Scientific's Learning Systems Group. More information can be found by visiting the Freedom Scientific Website.)

Artic Technologies - Simply Computers
1000 John R. Road
Suite 108
Troy, Michigan 48083
Phone:(248) 588-7370
Website:
http://www.artictech.com

Dolphin Access Systems
60 East Third Avenue,
Suite 130
San Mateo, CA 94401USA
Phone: (866) 797 5921
Website:
http://www.dolphinusa.com

Don Johnston, Inc.
26799 West Commerce Dr.
Volo, IL 60073
Phone: (800)999-4660
(US & Canada)
(840)740-0749
(US & Int'l)
Website:
http://www.donjohnston.com

Dragon Systems
ScanSoft, Inc.
9 Centennial Drive
Peabody, MA 01960
Phone: (800) 654-1187
(USA)
(978) 977-2452 (Int'l)
Website:
http://www.dragonsys.com
http://www.scansoft.com

Freedom Scientific
11800 31st Court North
St. Petersburg, FL
33716-1805
Phone: 800-444-4443
(within US)
727-803-8000
(worldwide)
Website:http://www.
freedomscientific.com

GW Micro, Inc.
725 Airport North Office Park
Fort Wayne, IN 46825 USA
Phone: (260)489-3671
Web Page:
http://www.gwmicro.com

IBM Corporation
IBM Accessibility Center
11400 Burnet Road,
Austin, TX 78758
Phone: (800) 426-4832
Website:http://
www-3.ibm.com/able/

Infogrip, Inc.
1794 E. Main Street
Ventura, CA 93001
Phone: (800) 397-0921
(805)-652-0770
Website:
http://www.infogrip.com

Inspiration Software, Inc.
7412 SW Beaverton
Hillsdale Hwy
Portland, OR 97225-2167
Phone: (800) 877-4292
Website:
http://www.inspiration.com

Intellitools, Inc.
1720 Corporate Circle
Petaluma, CA 94954-6924
Phone: (800) 899-6687 (USA)
(800) 353-1107 (Canada)
(707) 773-2000 (Global)
Website:
http://www.intellitools.com

Interlink Electronics, Inc.
546 Flynn Road
Camarillo, CA 93012
Phone: (800) 340-1331
Website:
http://www.
interlinkelectronics.com

Kensington Technology Group
Corporate Headquarters
2000 Alameda de las Pulgas
Second Floor
San Mateo, California
94403-1289
Phone:(800)235-6708
(North America)
(650)572-2700
(Outside North America)
Website:
http://www.kensington.com

Kurzweil Educational
Systems, Inc.
14 Crosby Drive
Bedford, MA 01730-1402
Phone:(800) 894-5374
(USA or Canada)
(781) 276-0600
(other countries)
Website:
http://www.kurzweiledu.com

Lernout &Hauspie
Now part of ScanSoft, Inc. For more information, see the contact information for Dragon Systems/ScanSoft.

Next Generation
Technologies
20006 Cedar Valley Rd
Suite 101
Lynnwood, WA 98036-6334
Phone: (425) 744-1100
Website:
http://www.ngtvoice.com

Origin Instruments
Corporation
854 Greenview Drive
Grand Prairie, TX
75050-2438
USA
Phone: (972) 606-8740
Website:
http://orin.com/index.htm

Papenmeier
F.H. Papenmeier GmbH
& Co. KG,
P.O. Box 1620
D-58211
Schwerte, Germany
Phone: +49-2304-205-0,
Website:
http://www.papenmeier.de/

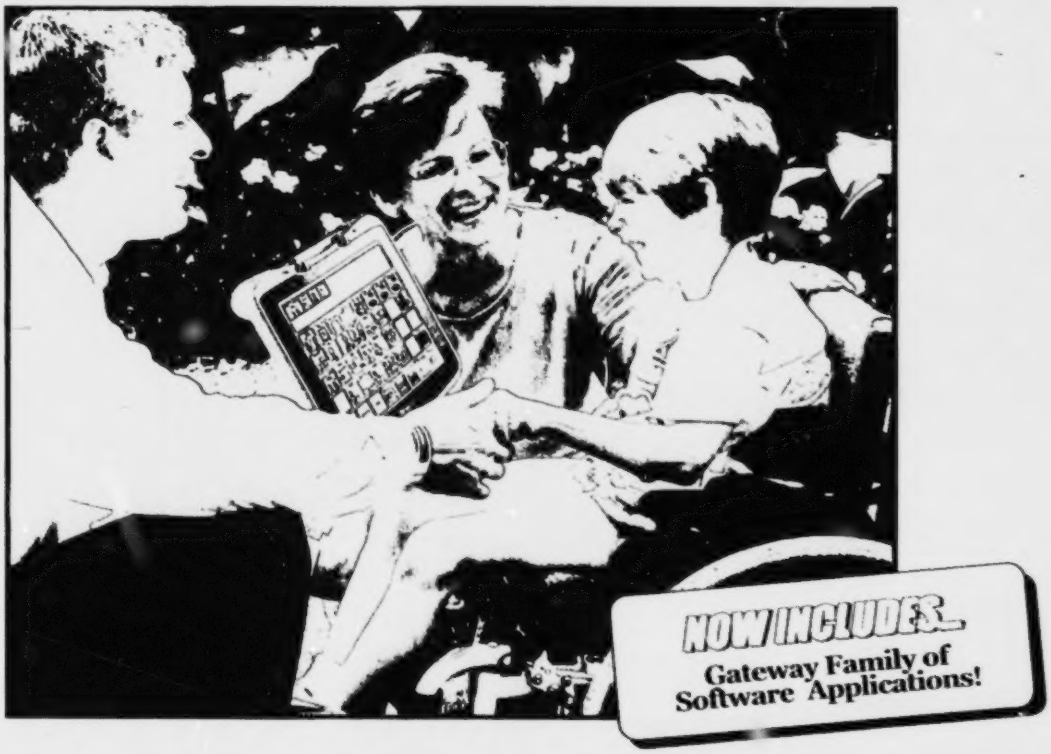
Penny & Giles
Computer Products
1 Embankment Way
Castleman Industrial Estate
RINGWOOD
Hampshire
BH24 1EU
United Kingdom
Phone:+44 (0)-1-425-463100
Website: http://www.
penny-gilescp.co.uk/

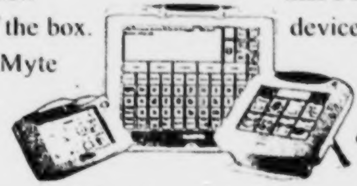
Prentke Romich Company
1022 Heyl Road
Wooster, OH 44691
Phone: (800) 262-1933
Website:
http://www.prentrom.com/
http://www.prentromint.com
(outside US)

Tash Inc.
3512 Mayland Ct.
Richmond VA 23233
Phone; (800)463-5685
Website:
http://www.tashinc.com

TechAble
1114 Brett Drive
Conyers, GA 30094
Phone: (770)922-6768
WebSite:www.techable.org

Communications for Life Just Got a Whole Lot Easier.


NOW INCLUDES...
Gateway Family of Software Applications!



Now even more DynaVox communication solutions are available to you right out of the box. When you order a new DynaVox or DynaMyte communication device, or DynaVox software from DynaVox Systems, you'll now receive Gateway to Language and Learning, Gateway 54 and Gateway Junior, all developed by Joan Bruno, Ph.D., CCC-SLP at no additional cost! Plus, as an added convenience, we will install all three Gateway software programs on the device before it is shipped to you. More communicators will enjoy all the benefits of having a pre-designed vocabulary system that's ready to use as soon as their DynaVox device arrives.

DynaVox products have been helping people to communicate for nearly two decades. All of the professional associates at DynaVox are committed professionals dedicated to preserving dignity and pride...offering compassion and understanding...providing first quality communication products for the ones you love the most.

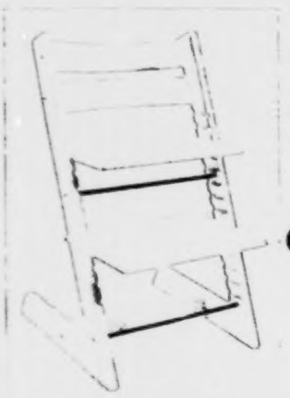
By making Gateway part of the DynaVox package, we're staying in touch with the kind of communication solutions that professionals want and our customers need.

BEST COPY AVAILABLE

DYNAVOX
a division of
SUNRISE MEDICAL
inTouch with Communication Solutions for Life.

For more information please contact our inside sales department at:
1-888-697-7332
www.dynavoxsys.com • e-mail: sales@dynavoxsys.com

Circle #34 or visit www.eparent.com/adinfo



We Like Making Kids Happy ...

Send For Free Catalog

equipment shop

P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094

E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #36 or visit www.eparent.com/adinfo

Discover
New England Village, Inc.

"A community rich with opportunity, sharing and growth."

Established as a non-profit corporation in 1972, New England Village is a warm, caring stable and secure environment where young adults with mental retardation can lead a high quality lifestyle with opportunities for growth and friendship.

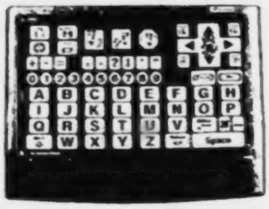
Our campus, set on 80 beautifully wooded acres just 25 miles south of Boston, offers attractive contemporary style homes and townhouse apartments. Learn about our full range of residential options, extensive vocational and education programs, and wide spectrum of recreation and social opportunities. We invite you to meet our dedicated and caring staff and speak to other families about our village.

Call (781) 293-5461, or write Judy Andracchio, Admissions Coordinator, to arrange your personal visit or request our brochure. We invite private and state-sponsored referrals.

New England Village, Inc.
664E School Street • Pembroke, MA 02359
781-293-5461 • website: newenglandvillage.org
email: info@newenglandvillage.org

continued from page 29

an additional switch (see Switch Access below) replaces the mouse button. Combining a head pointing system with an on-screen keyboard allows full computer control to someone who cannot use a standard keyboard and mouse.



Infogrip's Discover:Board™

Switch Keyboard and Mouse Access Using Scanning or Morse Code

When a person's mobility impairment prevents the use of a standard keyboard or mouse, using a switch may be a possibility. Switches come in a wide array of styles and can be controlled with nearly any body part. Switches can be activated with a kick, swipe of the hand, sip and puff by mouth, head movement, eyeblink or touch. Even physical closeness can activate a proximity switch. These switches work in concert with a box or emulator that sends commands for the keyboard and/or mouse to the computer.

There are a variety of input methods that rely on switches. Scanning and Morse code are two of the most popular. Upon activation of a switch, scanning will bring up a main menu of options on the screen. Additional switch activations allow menu items to be narrowed down to the desired keystroke, mouse or menu action. Morse code is a more direct method of control than scanning and, with practice, can be a very efficient input method. Most learners quickly adapt to using Morse code and can achieve high entry speeds.

Switch systems should be mounted with the assistance of a knowledgeable professional, such as an occupational therapist. If mounted to a wheelchair, it is important that switch mounting does not interfere with wheelchair controls. Seating and positioning specialists can also help determine optimum placement for switches, reduce the time in discovering the best switch system and maximize positive outcomes.

Speech Recognition

Speech recognition software converts words spoken into a microphone to machine-readable format. The user speaks into the microphone either with pauses between words (discrete speech) or in a normal talking manner (continuous speech). The discrete speech system, although slower, allows the user to identify errors as they occur. In continuous speech systems, corrections are made after the user is finished speaking. Speech recognition technology requires that the user have moderately good reading comprehension in order to correct the program's text output. Voice and breath stamina should also be a consideration when evaluating speech recognition as an input option.

Reading Systems

An individual who has a difficult time holding printed material or turning pages may benefit from a reading system. These systems are typically made up of hardware (scanner, computer, monitor, and sound card), Optical Character Recognition (OCR) software (e.g., Arkenstone's WYNN or Kurzweil 3000), and a reading/filing program. The system provides an alternative to reading printed text. Hard copy text is placed on the scanner where it is converted into a digital image. The image is then converted to a text file, making the characters recognizable by the computer. The computer can then read the words back using a speech synthesizer and simultaneously present the words on screen.

Low-Tech Tools

Not all assistive technology for people with mobility impairments is computer-based. The use of such common items as adhesive Velcro to mount switches or power controls can provide simple solutions to computer access barriers. Often, tools of one's own making can provide the most effective and comfortable accommodations for mobility impairments.

SENSORY IMPAIRMENTS

As computers and operating systems have become increasingly sophisticated, adapting computers for use by people with sensory impairments has posed increasing challenges. Because sound was rarely used, people with hearing impairments experienced few limitations in operating the early personal computers. Not long after the introduction of the personal computer, software and hardware systems for reading screen text out loud were developed for people with visual impairments.

The advent of graphical interfaces (e.g., Microsoft Windows™ and Macintosh OS™) complicates computer access for people who cannot see the screen, since their speech output systems are designed to read text. Multimedia output that uses audio is not accessible to

continued on page 34

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Serving Adults having MR/DD

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #19 or visit www.eparent.com/adinfo

continued from page 33

those people who cannot hear and people who cannot feel a keyboard cannot type effectively. Fortunately, specialized hardware and software can make computer systems usable by individuals with a sensory impairment.

VISUAL IMPAIRMENTS

The most common accommodation for a computer user with a visual impairment is to enlarge the display of a monitor. This is accomplished using screen enlargement software. Various screen enlargement packages offer a variety of features. The most popular features enlarge the display from two to 16 times the normal view and invert screen colors for those who are sensitive to the usual display of white text on a black background. Some enlargers also incorporate speech output to reduce the strain associated with reading large blocks of text. Commonly used enlargement software includes ZoomText Xtra™ (Ai Squared), Magnum™ (Artic), MAGic™ (Freedom Scientific), and Lunar™ (Dolphin Access Systems).

Screen enlargement technology combined with a scanner can be used to magnify printed text. Once a page is scanned using a standard desktop scanner, the results are displayed in large print on the computer screen.

People who are blind access computer output with speech and/or Braille output systems. Speech output is the most popular form of access. A variety of products have been created for working with the Microsoft Windows™ operating system. Most people who are blind use a standard keyboard as an input device, since using a mouse pointer requires accurate eye-hand coordination. Screen reader software uses pre-defined key combinations for review and navigation of the computer screen and is usually compatible with most standard software, including word processing, Web browsing and electronic mail. Examples include, but are not limited to, HAL™ and SuperNova™ (Dolphin Access Systems), JAWS™ for Windows (Freedom Scientific), outSPOKEN™ (Alva Access Group), and Window-Eyes™ (GW Micro). People who are blind using a Macintosh are limited to outSPOKEN™.

Refreshable Braille displays are devices that echo information from the screen to a panel with Braille cells. Within the cells are pins that move up or down based on the text transmitted. Braille displays can provide very effective accommodations for users who require precise navigation and editing, such as when creating computer program code that isn't pronounced well with speech. Displays such as the BRAILLEX™ (Papenmeier) and Delphi™ (Alva Access Group) also provide navigation and orientation information to the computer user who is blind.

For novice screen reader users who need access to the World Wide Web, consider dedicated Web browsing software that incorporates speech and/or large print. These browsers ease the process of navigating complicated Web sites, and simplify Web

HDIS

Convenient Home Delivery of Bladder Control Products

Get your Huggies® Little Swimmers® year-round at HDIS!

FREE Sample

- Protects in the water without swelling up like diapers.
- Tear away sides make changing easy.
- Can be worn under a swimsuit or alone.

Small (16-26 lbs.)
Medium (24-34 lbs.)
Large (32+ lbs.)

Huggies® Little Swimmers®

Call now for a FREE sample!
Call 1-800-2MY-HOME®
(1-800-269-4663)

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

"We're here to help make your life a little easier."
– Mary

©2002, HDIS
024-130

Circle #41or visit www.eparent.com/adinfo

searching as well as reading of Web sites. Home Page Reader™ (IBM) and Connect Outloud™ (Freedom Scientific) are two of the many examples of this kind of software.

HEARING IMPAIRMENTS

There are few adaptations available (or necessary) for people with hearing impairments using standard computer productivity software. Sound is used little in mainstream applications such as word processing or e-mail and, when it is used, there is often a visual alternative. Built-in operating system features found in the control panels of Windows software and the Macintosh computer provide visual displays for system-generated beeps.

The increasing use of streaming multimedia is a concern for those who can not hear. Content developers rarely include captioning in video presentations, nor do they transcribe the audio into text. Resources from the National Center for Accessible Media (NCAM) and Microsoft are available for content developers to add captioning to streaming video.

LIMITED SENSITIVITY

Loss of sensitivity in hands and/or fingers due to peripheral neuropathy or other causes can make it difficult or impossible to use a standard keyboard and mouse. People with this type of sensory impairment can benefit from the use of speech input software such as NaturallySpeaking™ (Dragon Systems) or Voice Xpress™ (Lernout & Hauspie) to control a computer and enter text. Because Neuropathy may be accompanied with vision loss, use of speech output may also be required. JawBone™ (Next Generation Technologies) is middleware—software that serves as a go-between for

continued on page 36

Shopping solo

Chase, a 19-year-old with autism, can now tolerate the noise and overhead music in the store. He's learned to ignore the candy and chips, to choose nutritious foods without the help of props or pictures. Back at Heartspring, he neatly puts the groceries away and sets the table. After dinner he washes and dries the dishes. With only a little supervision. And with a lot of pride.

HEARTSPRING™
SCHOOL
Finding New Ways for Learning
8700 East 29th Street North · Wichita, Kansas 67226
call 1-800-835-1043
www.heartspring.org

Circle #21 or visit www.eparent.com/adinfo

continued from page 35

two other programs—that allows JAWS screen reading software to work with Dragon NaturallySpeaking.

EMPOWERING THE USER

It is important to remember that the specific need for adaptive technology is unique to the individual. Trial-and-error may be required to find a set of appropriate tools and techniques. The end user—the person with a disability—should play a key role in determining what works best.

Sheryl Burgstahler, PhD, is the Director of DO-IT, Co-director of Access IT, and Assistant Director of Information Systems at the University of Washington.

Dan Comden is the Manager of the Adaptive Technology Lab at the University of Washington. In that position he helps students, faculty and staff select and use adaptive technology and consults with campus units about making their computer labs and Web pages accessible.

Acknowledgements: This article is based upon work supported by the National Science Foundation under grant number 9800324. Any opinions,, findings, and conclusions or recommendations expressed in this article are those of the authors and do not necessarily reflect the views of the National Science Foundation. More information of this topic can be found at http://www.washington.edu/doit/Brochures/Technology/.

About DO-IT

DO-IT (Disabilities, Opportunities, Internetworking and Technology) serves to increase the participation of individuals with disabilities in challenging academic programs and careers. It promotes the use of computer and networking technologies to increase independence, productivity and participation in education and employment. For further information, contact:

DO-IT
University of Washington
Box 355670
Seattle, WA 98195-5670
doit@u.washington.edu
http://www.washington.edu/doit/
206-685-DOIT (3648) (voice/TTY)
888-972-DOIT (3648) (voice/TTY)
WA, outside Seattle
206-221-4171 (FAX)

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel.** Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #39 or visit www.eparent.com/adinfo

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C.
& Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at
www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #50 or visit www.eparent.com/adinfo

Technologies for People with Cognitive Disabilities

TECHNOLOGY

In Education & Daily Living

by Vanessa B. Ira

The Coleman Institute seeks integration of high tech into daily life.

The Coleman Institute's Associate Director, Michael Lightner, Director of Advancement, Enid Ablowitz, founders Claudia and Bill Coleman, and Executive Director David Braddock (l-r).

Early last year, the University of Colorado received a $250-million gift endowment from William "Bill" Coleman, III. The gift is being paid over a period of five years toward the building of the University of Colorado's Coleman Institute for Cognitive Disabilities. Bill and his wife, Claudia, had decided that they would give back to society, doing so for the community of people with special needs—while harnessing his knowledge of computers, honed from the early years of his career as an executive at Sun Microsystems. Coleman is currently the chairman and CEO of his own company, BEA Systems.

"In 1993, I ran software development for Sun Microsystems and because of some success, I was able to retire." Bill relates. "But I didn't know what I wanted to do. I've always been a goal-oriented person. When I was in the Air Force, I said when I'm done I'll run a Fortune 500 computer company by the time I am 45. I made that by the time I was 41. Then I set a goal to build a $100-Million software company from scratch by the time I was 50. At 45, I set a goal for when I reached 55: I would create what I called a 'life to go to' —a life that would make me excited about getting up every morning until I'm 80.

"I decided that I wanted to have a balance between three things: one, being involved in the computer industry; two, giving back, particularly for the disabled; and three, spending some time on civic activities and traveling."

The Colemans had a personal interest in wanting to aid people with special needs having witnessed their niece, who has cognitive disabilities, grow up and benefit from the use of a computer starting at the age of 5. "She's now working, helping out in a hospital," Coleman says. He is proud of his niece's achievements, although he also notes that she has not been able to live independently. Here, he feels, lies the role of technology.

"As the world becomes more wired, systems around you are going to become aware as well," Coleman explained. "For example, helping you get to your hotel room and having the system be able to unlock the door for you-these are the kind of things that will really help people with cognitive disabilities be able to relate to their environment in a much-better way, on an individual basis."

The goal for Coleman's philanthropy was to be able to fund two parts, first by building a permanent endowment for the research that is turned into the Coleman Institute. "But it had to be enough of an endowment that it could provide a center of excellence," Bill stresses. "What I worry about in this area is that nothing is integrated. It's all being done by providing a small grant here and a small something there. There's no way to really leverage where technology and the whole clinical research area are going. What we're doing is moving within the areas of research, to computer science and cognition, special education, all the way to the family community."

The Colemans began building the foundation of the Institute for Cognitive Disabilities by gathering a team of accomplished individuals to set the wheels in motion.

David Braddock, PhD, came on board as executive director and associate vice president for research for the University of Colorado in August of 2001. He is the former president of the AAMR, the former head of The Department of Disability and Human Development at the University of Illinois at Chicago and is an expert on the study of cognitive disabilities. Currently, the Institute is sponsoring 13 research grants on cognitive disabilities for the four-campus system. The Institute also recently concluded a national conference on Philanthropy in Developmental Disabilities for University-based centers in DD from 36 states, co-sponsored by the Association of University Centers on Disabilities.

Michael Lightner, PhD, serves as the Institute's associate executive director. He is also associate dean for special projects and professor of electrical and computer engineering, as well as vice president for technical activities for the Institute of Electrical and Electronics Engineers.

Elizabeth Hoffman is the president of the four-campus University of Colorado Systems which has 46,000 students.

Bill Coleman will be actively involved with the Institute, as will Claudia, who is a former manager for Hewlett-Packard.

"One of the things we've done was set up this Institute and set it up so that the Institute reports to the University," Bill says. "And it owns all the intellectual property. Now, the reason for that is I believe there will be what we call the 'space program effect' from the 60s. There'll be a huge market for companies to adapt this technology for many commercial reasons. The royalties from that should come back into the Institute to build endowments so that we can even continue to increase the research. The byproduct of the endowment are fellowships and scholarships that would form a base of academic and clinical research and other experts."

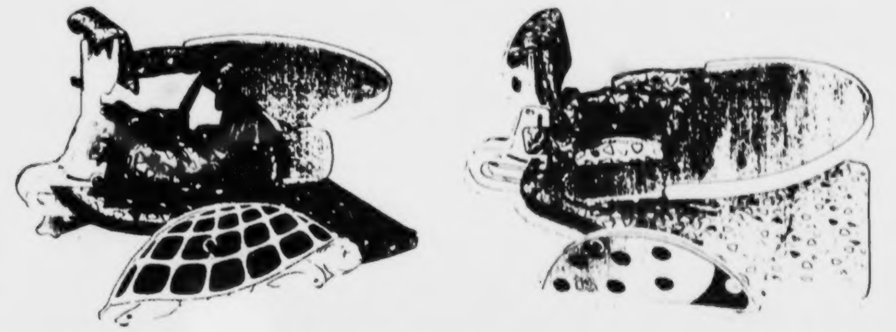
Coleman looks to developing such an integrated system that continues to endow research so it is richer and fuller and expansive across all the campuses of the University of Colorado and also in other universities.

On the subject of how people learn and retain, Coleman explains: "Now we can build a computer model. We can build tools, such as what's going on now with 'personalization' that can actually adapt to interfacing with individuals, based on not just their disabilities, but also on the individual's way of learning and adapting. You can build a database over time. In a world where everything's connected going forward, that system can interact with systems around you. When there's a problem, there can be real-time connectivity to real practitioners and helpers, who are somewhere else, anywhere in the world."

"To me, the natural advances of technology, and the ways they are being implemented, are going to provide the infrastructure to do this. What we need to do is provide the ability to continually build this taxonomy, the systems and support structures that can continually learn to adapt better to the abilities and disabilities of individuals, their personal learning and retention. We need to understand that and how best to interact with it. I mean, they're going to have global positioning satellites go right into it. That's already coming because of these wireless applications. They're going to know right where you are."

Coleman's years at Sun Microsystems have helped shape his vision for technological research at the Institute: "Our vision was centered on the idea of the network becoming the computer. The convergence of communication and computing would mean that what we considered a portable telephone 10 years ago would have all of the capabilities of computer or personal digital assistant, telephone and everything. That device working on a network is going to do everything that a computer and a personal assistant can do. If the basic infrastructure is going to be there, endowing the research to be able to build the toolkit around it that adapts it to the mental condition, the learning abilities and cognition of the individual could be hugely reinforcing."

In the end, Coleman wants to "insure that that there be center of excellence. Once this really gets building, we want to fund a company that could exploit the technology as a non-profit. So that to the extent that company can make profits, all those profits will go into making the technology available to those who can afford it." ■



Stretch their body as well as their imagination.

These unique positioning tools have an innovative tilting seat that puts your child in a more functional position, encouraging reaching and extending, helping them with upper extremity and head control.

They're also built with the innovative Multi-grip™ hip guides that makes sitting more comfortable, thereby promoting a hamstring stretch that assists in the prevention of tight knees.

With all this stretching for their body, it's only a matter of time before they begin to stretch in other ways. At first a smile. Then, believing anything is possible.

JENX
Distributed by
BP
BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104
In Canada, call Advanced Health Care Products, Tel: 800-265-9830

Circle #23 or visit www.eparent.com/adinfo

THINKING READERS

Part II: Supporting Beginning Reading in Children with Cognitive Disabilities through Technology

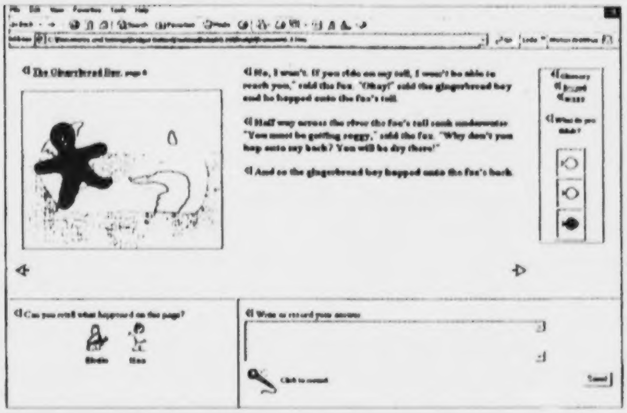
by Lucinda M. O'Neill and Bridget Dalton, EdD

Eleven-year-old Becky is totally absorbed in the electronic picture book on her computer screen, a digital retelling of the classic folk tale, *The Gingerbread Boy*. Using brightly colored illustrations and simple text, *The Gingerbread Boy* tells the story of a gingerbread cookie that escapes from the oven and has a series of encounters with animals who want to eat him. Becky, who has Williams syndrome, a genetic disorder that causes physical problems and developmental delays, has reached the part in the story where the gingerbread boy tries to cross a river by hitching a ride on the back of the wily fox.

"Oh, no," Becky exclaims, staring intently at the illustration showing the fox's back sinking into the water as the gingerbread boy perches on his head. "What do you think about that?" asks Peggy Coyne, a CAST researcher. "He'll drown," Becky predicts. She clicks on the text to have it read aloud to her and then quickly moves to the next page to find out what happens next. "Oh, no," she cries out again as she looks at the illustration of the fox sitting on the river bank, licking his lips "he (the fox) ate him!" "How do you know?" asks Peggy. "Because I don't see him!" Becky exclaims.

Later, a learning prompt embedded in the digital picture book asks Becky to describe her favorite part of the story, either by typing her response in a text box or recording her response orally. "My favorite part of the story is when the fox ate the gingerbread boy," she says. "Do you want to type that?" Peggy asks. "No, I want to record it," she responds decidedly. Becky records her response three times before she is satisfied, smiling and clapping her hands at her accomplishment.

Above: Becky, who reads at the first-grade level, builds oral fluency by retelling the story of the Gingerbread Boy using the program's recording feature. Inset: The wily fox character. (Illustration by Kathy Dalton.)



"No, I won't. If you ride on my tail, I won't be able to reach you," said the fox. "Okay!" said the gingerbread boy and he hopped onto the fox's tail.

Half way across the river the fox's tail sank underwater. "You must be getting soggy," said the fox. "Why don't you hop onto my back? You will be dry there!"

And so the gingerbread boy hopped onto the fox's back.

Can you retell what happened on the page?

Write or record your answer

Above: Sample screenshot from CAST's digital version of The Gingerbread Boy© with embedded reading supports for children with cognitive disabilities.

Left: Using the Thinking Reader picture book program, James (pictured with CAST's Bridget Dalton), is in control of the computer and the mouse.

Raising expectations

It is an unfortunate truth that many children with severe cognitive disabilities have not had the opportunity to fully realize their potential because of low expectations for their development in the area of literacy. With conventional approaches to teaching reading, children with such disabilities often are not able to learn to read at a functional literacy level. Traditionally, literacy instruction for these children has focused on drill and practice; however, recent research by Koppenhaver and Erickson and their colleagues at the Center for Literacy and Disabilities Studies suggests that these students benefit from the same research-based instructional approaches that work for other students who are learning to read. That is, reading instruction that:

- Focuses on reading for meaning,
- Provides direct instruction in reading skills such as phonics and decoding (word recognition), and
- Offers children a wide choice of appealing literature.

Becky is one of seven children with cognitive disabilities who are involved in CAST's Thinking Reader Project. Funded in part by the Joseph P. Kennedy, Jr., Foundation, the project draws on a well-established research base in how children learn to read as well as a new educational approach pioneered by CAST called Universal Design for Learning, which weds current research in how the brain learns with the flexibility of multimedia computer technology. The project is creating digital versions of popular children's stories that include a variety of built-in supports for the development of beginning reading skills in children with cognitive disabilities. "The project is about expanding possibilities and raising expectations for the literacy development of these children," says David Rose, CAST's co-executive director.

A powerful teaching tool

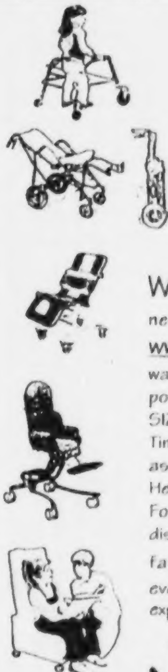
Unlike traditional print books, digital text has the flexibility to change in relation to the instructional goal and the individual learner's characteristics. The Thinking Reader picture books provide three instructional foci: comprehension strategies, story grammar, and decoding. In the opening scenario, the instructional goal was comprehension and Becky's attention was focused on making sense of the story. Decoding was not an issue, since she could click on the text to have it read aloud. On another day, the instructional goal might be word recognition. When working on oral reading, Becky clicks on the decoding supports to help her sound out the words and practices reading aloud into the computer microphone. She records and listens to herself read, engaging in repeated readings that help her build her word recognition skills. On yet another day, Becky learns about character and plot as she responds to story grammar prompts. The Thinking Reader's flexibility in enabling teachers to set the goal of a learning activity increases Becky's opportunities for success and keeps her engaged in the targeted learning task for extended periods.

While it is possible for children to read electronic storybooks by themselves after some initial training, the Thinking Reader is designed to support an instructional dialogue between the child and a teacher or instructional aide. Students are put in charge of the computer mouse

continued on page 42

Adaptivemall.com™

Shop On-line!



Tim's daughter Carrie.. a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment...........and OT/PT on-line SIZE HELP facilitates your selection.
Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

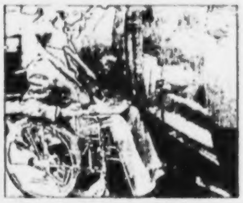
Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #22 or visit www.eparent.com/adinfo

DRIVE-MASTER

50 YEARS of Providing Mobility for the Physically Challenged



STEERING YOU IN THE RIGHT DIRECTION

Innovators Then...

Partial Features Include...

- Hand Controls
- Reduced Effort Steering
- Reduced Effort Braking
- Foot Steering
- Left Foot Gas Pedals
- Wheelchair Lifts
- Porch Lifts
- Steering Devices
- Backup Brakes & Steering
- Horizontal Steering
- Complete Van Conversions
- Block Pedal Extensions

Experts NOW!

DRIVE MASTER

9 Spielman Road, Fairfield, NJ 07004-3403
Phone: (973) 808-9709 • Fax: (973) 808-9713
E-mail: drivemaster@drivemaster.net
Web: www.drivemaster.net

And Much More!
For additional info.
contact Drive-Master

24 HOUR TURNAROUND SERVICE

Circle #32 or visit www.eparent.com/adinfo

continued from page 41

and choose many of the activities they want to pursue within the program. The teacher plays a key role, guiding students in responding to the learning prompts embedded in the stories. "It allows the teacher to have a conversation with the child about the text, moving beyond a rote response to the story or an over-reliance on yes and no responses," says Ron MacAdow, an instructional designer and manager of the Thinking Reader Project.

For example, asking students to retell a story in their own words is an exercise that contributes to both comprehension and the development of verbal skills. Erica, a student with cognitive disabilities for whom English is a second language, retells the story sequence in which the fox eats the gingerbread boy. "The fox say hop on my back, my tail is soaking wet," Erica relates. Moving to the next screen, where the fox is shown sitting alone in the grass licking his chops, she laughs out loud. Next, she clicks on the picture and hears the fox say, "Mmm, mmm, I love to eat gingerbread cookies," confirming her guess about the fate that has befallen the gingerbread boy. "At the end, he (the gingerbread boy) didn't listen again, all the time the cookie didn't listen. He doesn't have a brain," Erica concludes, laughing again.

A promising beginning

By providing children with cognitive disabilities with supports that enable them to make progress in all aspects of language and literacy development—reading, writing, listening, and speaking—CAST believes that the Thinking Reader and similar programs can help these children can take critical steps towards independence.

Teachers report that they see their students actively reading and responding to the digital picture books in ways they haven't seen before in traditional reading instruction. "I think it's wonderful," one teacher says, citing the levels of support the program offers and the opportunities for children to "take charge of their learning" as specific strengths of the approach. "Children have definite ideas about what they liked about their work," she observes, commenting on how the program offers students the opportunity to listen to their own voices and review their progress. Another teacher commented that the program promotes students' oral language, noting that she observed one child talk more in a single session reading on the computer than she had in the previous five weeks of class.

Parents are also eager to see tools like this more available in classrooms. "I think it's been very positive," Becky's mom says of Becky's involvement in the program. "Her reading is taking off. Before I thought her reading was more sight words or from memory, and now we can be out on the street and I'll say, 'What does that say?' and she can tell me."

CAST's current work with children with cognitive disabilities builds on a three-year study the organization conducted with a different group of "Thinking Readers"—middle school students with learning disabilities (*Exceptional Parent*, June 2001). In this U.S. Department of Education-funded study, CAST researchers evaluated the Thinking Reader approach with 102 students, most with learning disabilities and all performing below the 25th percentile in reading. The study demonstrated that students who used supported, digital versions of age-appropriate novels had greater comprehension gains on a standardized reading test than did a control group of students who did not use computer supports. The students who used computer-based supports also showed higher levels of engagement when interacting with the material and improved "on task" behavior.

Future directions

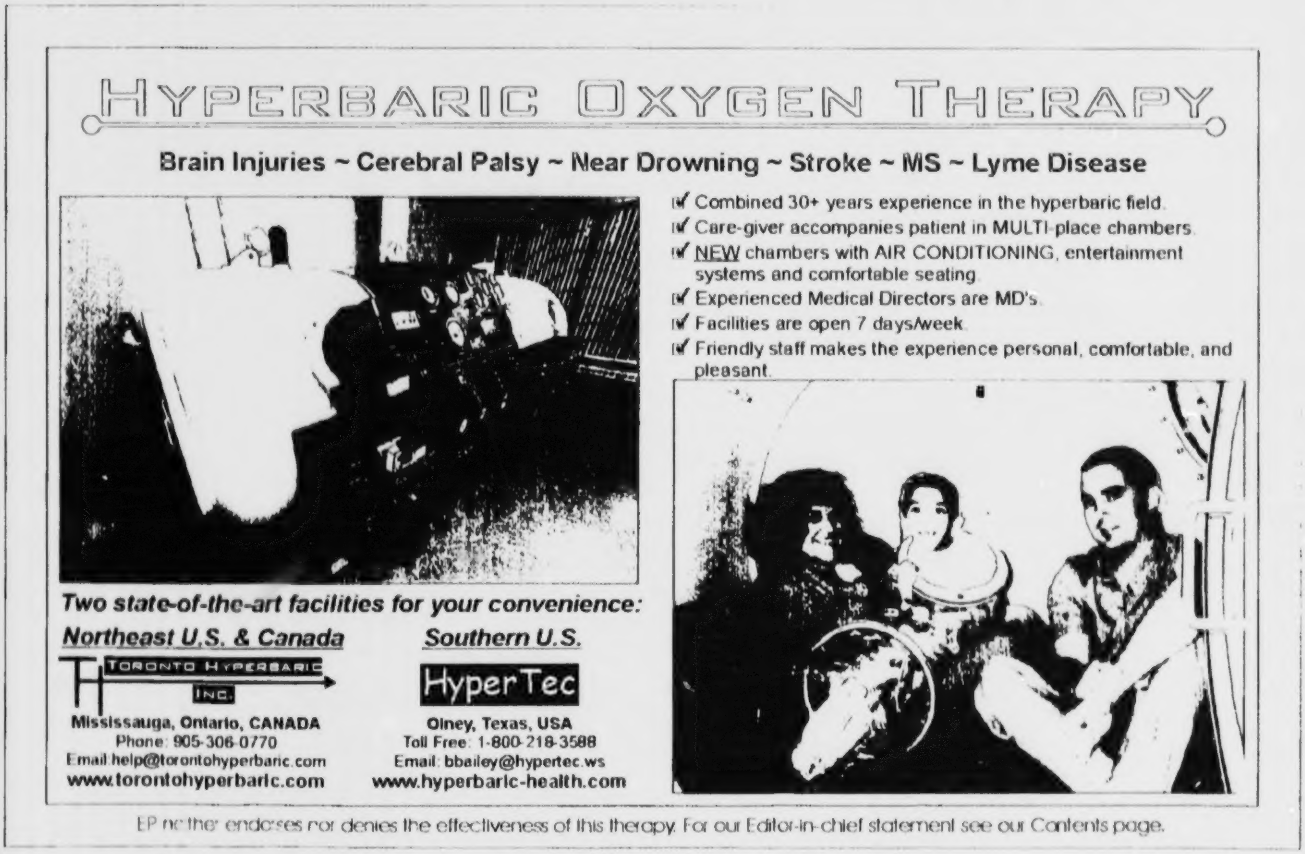
There is a growing body of research demonstrating the positive impact of computer-supported reading instruction and electronic picture books on students' literacy development. CAST believes that supported digital learning environments are the future of educational technology, and that designing effective learning environments for those students with more severe learning needs will result in more effective learning for all. EP

Lucinda M. O'Neill is a staff writer at CAST, the not-for-profit Center for Applied Special Technology in Peabody, MA. Bridget Dalton, EdD, is Chief Education Officer of CAST.

Suggestions for further reading

Rose, D. & Meyer, A. (2002). *Teaching Every Student in the Digital Age: Universal Design for Learning.* Alexandria, VA: Association for Supervision and Curriculum Development.

National Reading Panel:
http://www.nationalreadingpanel.org



HYPERBARIC OXYGEN THERAPY

Brain Injuries ~ Cerebral Palsy ~ Near Drowning ~ Stroke ~ MS ~ Lyme Disease

- ✓ Combined 30+ years experience in the hyperbaric field.
- ✓ Care-giver accompanies patient in MULTI-place chambers.
- ✓ NEW chambers with AIR CONDITIONING, entertainment systems and comfortable seating.
- ✓ Experienced Medical Directors are MD's.
- ✓ Facilities are open 7 days/week.
- ✓ Friendly staff makes the experience personal, comfortable, and pleasant.

Two state-of-the-art facilities for your convenience:

Northeast U.S. & Canada
TORONTO HYPERBARIC INC.
Mississauga, Ontario, CANADA
Phone: 905-306-0770
Email: help@torontohyperbaric.com
www.torontohyperbaric.com

Southern U.S.
HyperTec
Olney, Texas, USA
Toll Free: 1-800-218-3588
Email: bbailey@hypertec.ws
www.hyperbaric-health.com

EP neither endorses nor denies the effectiveness of this therapy. For our Editor-in-chief statement see our Contents page.

Circle #67 or visit www.eparent.com/adinfo

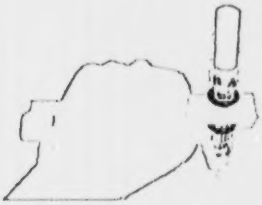
000 657

TECHNOLOGY
In Education & Daily Living

LOW-TECH—NO-TECH

Low-tech ideas that don't strain the brain or the budget and promote active participation in the home, school or community.

by Project Participate



Wooden Dowel Marker Support

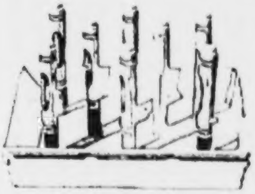
Drill a half-inch hole into a wooden dowel, insert a marker, add two rubber washers to keep the marker secure and increase student participation in name writing or art assignments. Add a marker with letter or number stamps so student can practice writing the alphabet or counting.

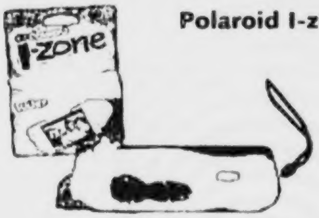
PVC Pen Holder

Construct a pen or pencil holder from the PVC pipe available at most home improvement stores and enable students with a gross grasp to doodle, draw or compose other written work. Drill a 1/4 inch hole into the center of a PVC "tee." Attach this PVC tee and another tee, to each end of a PVC "nipple." The parts are threaded and will screw together. Thread a thumb screw into the drill hole. Place a pencil, marker or paint brush into the tee and tighten with the thumb screw until secure.

Plaster Marker Holder

Instead of relying upon hand-over-hand assistance, enable students to select colors and recap markers independently with a weighted marker holder. Find a plastic container that will hold a one-inch base of plaster of Paris. Add plaster of Paris to the container, insert markers cap-end down and let the plaster harden.





Polaroid I-zone Camera

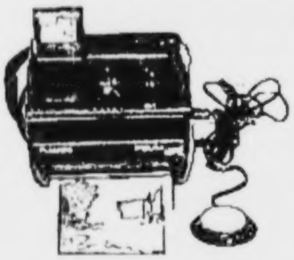
Increase participation in classroom assignments or homework with this inexpensive camera that takes and develops small photos on the spot. Insert special film with self-adhesive backing and attach photos easily to pages in binders, notebooks, poster paper or more!

Cookie Worksheets

Cookie sheets and magnets give students with decreased motor skills the ability to participate in many writing tasks. Students can slide magnetic numbers into numerical order, sort by odd or even status, attempt greater than or less than problems or add, subtract or multiply in math class. In language arts, students can use alphabet magnets to participate in activities such as letter identification, matching upper and lowercase letters or spelling tests.

Polaroid Camera

Photo essays make great alternatives to poster projects or term papers that entail lengthy detail or fine motor exertion. Polaroid cameras produce photos on the spot for instant satisfaction and results. Students can use the cameras to document lab assignments or other research findings. EP



Adapted from "Gadets & Gizmos" on the University of Colorado Health Science Center's Project Particpate Web site:http://projectparticipate.org Project Participate provides families, educators, administrators and therapists with simple strategies to increase the active participation of students with disabilities in school programs. Project Participate's Web site is supported by a US Department of Education (OSEP)grant (H324M980258). This site designed by Kristine Lachina, Teri Brogdon, Steve Rosenberg and Electronic Storefronts, Inc. For more information, contact: Project Particpate, University of Colorado Health Science Center, 4200 E. 9th Avenue, C221, Denver, CO 80262; telephone: (303) 864-5277; fax: (303) 864-5270 http://projectparticipate.org.

Discover the faces of Children's Hospital

Everyday we take special care of children. From broken bones to long-term care, from infants to teens. It's our understanding of children and their families that makes us unique.

For over 80 years now, Richmond's Children's Hospital has been providing specialty pediatric care. We understand children. And what it takes to tailor our services to their individual needs.

Take for example, our Pediatric Feeding Disorders Program, one of only a few such services in the country.

Or our Inpatient Rehabilitation Program which helps children who have experienced trauma, disease or impairments return to the activities of daily life.

For adolescents who need subacute care to babies who have never seen the outside world, our Transitional Care Unit is a step toward home. And a place where parents learn to care for their child's special needs.

Discover where children come first.

Children's Hospital

Specialty Services for Children

2924 Brook Road • Richmond, Virginia 23220-1298
(804) 228-5818
www.childrenshosp-richmond.org

We accept most commercial payors, Medicaid HMO's and Medicaid.

Circle #25 or visit www.eparent.com/adinfo

ASSISTIVE TECHNOLOGY STUDY Begins

by Vince Wetzel

In a move toward grass-roots based research, the National Institute on Disability and Rehabilitation Research (NIDRR) has awarded a five-year, $300,000 per year grant to the California Foundation for Independent Living Centers (CFILC) for unprecedented, in-depth study on the benefits of assistive technology to people with disabilities. The work is getting under way.

As part of the grant, CFILC is incorporating its 29 independent living centers throughout California to work with its members and stakeholders. They are collecting research data on access and use of AT to improve the lives of people with disabilities. Researchers from California State University at Northridge are training participants, including community advocates in research methods and to assist with data collection and analysis. These community advocates conduct focus groups, surveys and action research in their respective regions. Advocates will also train university students to do community-based research related to AT and independent living.

"NIDRR's decision to award the grant to CFILC recognizes the type of infrastructure already in place by the non-profit organization and its independent living center members," said Project Director Patricia Yeager, executive director of CFILC. "Normally, these grants go to Universities, who facilitate the research to a small sample. CFILC's approach allows researchers to train community advocates throughout the state for a larger and more representative sample."

Yeager went on to say, "It's also important to note that consumer involvement is key. We are not doing research on people with disabilities and AT. We are doing research *with* people with disabilities on the effects of AT in their lives."

The Technology for Independence Project is looking at the impact of assistive techology on the lives of its stakeholders, including those with disabilities, their families, friends and employers. CFILC's AT Community Research Network has identified four areas where it will continue to concentrate its efforts, though the research is not restricted to those areas. Those areas are:

Employment Outcomes—With emphasis shifting from helplessness to work, the impact of AT in the workplace is being examined. The Research Network is looking at types of equipment which are helpful in the workplace for people with a wide variety of disabilities doing a range of jobs. The findings will help employers, rehabilitation counselors, secondary guidance counselors and teachers.

Health and Function Issues—This area is focusing on a person with a disability and his or her access to health services using AT. Successful implementation of independent living often depends on the tools that can maintain that independence. Access to accessible mammogram machines, weight scales and other health-related tools are critical to maintain independence. The research is looking at how AT impacts the health and independence of people with a wide variety of disabilities and on those who provide assistance to them.

Technology for Access and Function—Technology for access includes public and private spaces and uses. From digital telephones and their usage by non-digital hearing aid wearers to stair glides for seniors who do not want to move out of their home with stairs, the project is looking at how well AT can help in community and even family involvement. Research will help direct public policy makers to find the solutions needed to help implement the American with Disabilities Act (ADA) with regard to accessibility, public right of way, programs and information.

Independent Living and Community Function—One of biggest benefits to AT is community integration, whether it is giving a voice to someone who cannot speak or allowing someone to get out of his or her house. The project is looking at the common AT items that enable integration of people with a wide variety of disabilities and how those items are found and paid for. It also considers ways AT can be harnessed to provide more community integration throughout all cultural communities.

"By looking at these four criteria, our research will provide better insight into the importance of AT in the lives of people with disabilities," said principal researcher Dr. Tanis Doe, who directs the research project and assists in the teaching of research skills and analysis of the data. "Everyone from families to employers to government agencies will have a better understanding of AT and its impact on maximizing independent living and community integration."

enabled
ONLINE.COM

In the first year of the grant, the AT Community Research Network will report what is already known regarding the issues. Through a statewide conference with AT and independent living advocates and executive directors from the member ILCs in California, the Research Network will identify key issues and begin initial research training. At the conclusion of the year, community advocates will have been trained in methods to begin the project.

By the second year, the community advocates will begin collecting primary data and begin focus group moderation. The data will reveal what consumers need and want from AT and identify the consumers themselves. In the third year, AT Community Research Network will survey the data collection and look at the solid numbers and begin to draw conclusions from the data. It will also reach out to web-users to identify high-end

continued on page 48

THE MELMARK SCHOOL

2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Our approved private day and boarding school serves children ages 5-21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Acquired Brain Injuries
- Cerebral Palsy
- Mental Retardation
- Neurological Disorders

Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

We Offer Your Child:

- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK Ext. 636 or email admissions@melmark.org

Circle #52 or visit www.eparent.com/adinfo

continued from page 47

AT users and impact.

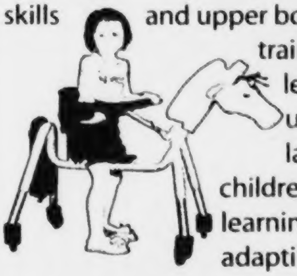
In the fourth and fifth years, the project will be in its final stages, and the AT Community Research Network will begin evaluating and disseminating information. By using data, the Research Network can evaluate the data itself and draw conclusions. These new conclusions, based on these new numbers, will be disseminated to show the impact of AT on individuals with disabilities.

"By year five, a lot of the questions regarding AT and the effect on the integration of people with disabilities in the family, community and workplace will now have solid data to go with abstractions," Dr. Doe said. "We all know AT helps people with disabilities live more independently, but we don't know how much. By the end, we'll have a better idea."

Research will help direct public policy makers to find the solutions needed to help implement the American with Disabilities Act (ADA) with regard to accessibility, public right of way, programs and information.

CFILC is a statewide, non-profit organization made up of more than two dozen Independent Living Centers. Through unified action, CFILC envisions civil rights for all people with disabilities. CFILC's mission is to support independent living centers in their local communities through advocating for systems change and promoting access and integration for people with disabilities. Visit the CFILC web site at http://www.cfilc.org for more information. EP

Vince Wetzel is the Director of Media Relations for CFILC (California Foundation for Independent Living Centers). He may be contacted at (916) 325-1690. This article is adapted by permission from EnabledOnline.com (http://www.enabledonline.com)



R.E.A.L. Design Introduces VIVO™
The New Multi -Therapy Pony

Children will love VIVO, the playful, spirited little pony with the head that bounces when moved and a colorful beaded tail. Parents and therapists will appreciate the valuable skills children gain by playing on VIVO because it functions as a balance rocker or gait trainer by simply interchanging the legs which snap on and off easily. As a rocking horse, VIVO promotes balance reaction skills and upper body postural development. As a gait trainer, it provides incentive for a child to learn ambulation skills. The soft upholstered seat back, with molded laterals, is height adjustable to position children comfortably and securely for rocking or learning to walk. Accessories are available for adapting VIVO to a child's positioning needs.

R.E.A.L. DESIGN 1.800.696.7041 Fax: 1.315.429.3071
www.realdesigninc.com

Circle #56 or visit www.eparent.com/adinfo

"Discover" NEW Opportunities

The Center for Discovery, a nationally-renowned prep school for children with significant disabilities (including multiple disabilities, medical frailties and some behavioral concerns) recently opened several new, small, universally-designed residences.

Located near Monticello, NY in the picturesque Catskill Mountains, just two hours northwest of New York City, The Center features a nature-based program that challenges children, and their families, to work with us to provide the finest educational, clinical, social and residential opportunities available anywhere.

We may just be
the right program
for your child.

Call our Admissions Office at (845) 794-1400, extension 1444 for information and/or to arrange a personal tour and see *discovery* in action.

Ask for our new video.

The Center for DISCOVERY

The Center for Discovery is certified by New York State through the State Education Department, the Department of Health and the Office of Mental Retardation and Developmental Disabilities (OMRDD), and by the Commission on Accreditation of Rehabilitation Facilities (carf).

Visit us at our Booth at The World Congress & Exposition on Disabilities in Orlando, Florida – October 3-5, 2002

Box 840 / Harris, NY 12742
845-794-1400, extension 1444
email: admiss@sdtc.org

Visit our websites:
www.thecenterfordiscovery.org
www.discoveryifi.org

BEST COPY AVAILABLE

Circle #66 or visit www.eparent.com/adinfo

LEGISLATIVE UPDATE

Federal Assistive Technology Legislation

1988-PRESENT

by Laura Noble

Does anyone remember the time before technology became such a regular part of our daily activities? Those were the days when people still drafted papers on typewriters, got up to change TV channels and had to get to a phone to make a call. Imagine still doing these things because you don't know about computers or remote controls or cell phones. Then think about how frustrating it is to learn about a tool that could ease your daily life—if only you could afford it.

For too many people with disabilities, advances in assistive technology are either unknown, unaffordable or both. For many others, though, their dreams of mastering their environment have become real through the use of assistive technologies. Federal laws enacted over the past two decades deal with "assistive technology"—the Technology-Related Assistance for Individuals With Disabilities Act of 1988 (the "Tech Act") and its successor, the Assistive Technology Act of 1998 ("AT Act").

The first law focused exclusively on assistive technology for people with disabilities. The Association for Tech Act Projects calls the Tech Act a "hallmark piece of legislation that has had a significant impact on the lives of persons with disabilities" and hails it as a "prototype" because of its "emphasis on consumer responsiveness, allowing consumers to be active partners in the process of knowing about, getting and using devices that meet their needs."

The main purpose of the Tech Act was to provide funding to states for the development of "consumer-responsible comprehensive statewide programs of technology-related assistance for individuals with disabilities." A secondary goal mandated the federal government to identify policies and barriers that impeded the provision of and payment for assistive technology.

The Tech Act set out specific components for statewide programs. These Tech Act programs were required to provide information about devices, services, legal rights and remedies; train people to locate and access funding sources for assistive technology; provide advocacy services and legal representation when assistive technology was inappropriately denied; and engage in legislative advocacy to ensure systemic changes in laws, regulations, policies and practices to enhance assistive technology rights. Additionally, states were expected to support the objectives of their Tech Act programs with "systems change and advocacy activities."

The first act created three-year development grants for states and then two-year extension grants. All states were funded at a minimum of $500,000 each per year while territories, such as Puerto Rico and the US Virgin Islands, received $150,000 each. Awards were based primarily on state size and population. Programs were administered by the National Institute on Disability and Rehabilitation Research (NIDRR) within the Office of Special Education and Rehabilitative Services (OSERS) of the US Department of Education.

The Tech Act represented enormous progress in the assistive technology field. "For the first time, the federal government created a definition of assistive technology that could be the standard benchmark for AT in other federal legislation, such as the Individuals with Disabilities Education Act (IDEA) and the Rehabilitation Act," said Ellen Lence. Lence is director of New Jersey's Tech Act program, the Technology Assistive Resource Program (TARP).

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) agrees. RESNA is a not-for-profit professional organization that seeks to improve the potential of people with disabilities to achieve their goals through the use of technology. The RESNA Technical Assistance Project continues to provide technical support to the 56 Tech Act projects through a grant from NIDRR. The law "was the first piece of legislation to use the term 'consumer responsiveness' and was the first piece of legislation to be so broad as to cover all disabilities and all ages," said Nell Bailey, Technical Assistance Project Director at RESNA. In fact, the first Tech Act legislation was passed before the Americans with Disabilities Act.

In 1993, Congress reauthorized the Tech Act, which changed the law's objectives and its funding scheme. According to Bailey, the reauthorization for program awards remained the same but the funding levels would be reduced as the programs reached their ninth and tenth years in operation. In the ninth year, Tech Act programs would receive 75 percent of their eighth-year funds and in Year 10, they would receive 50 percent of their eighth-year funds. By Year 10, federal funding for the program would end altogether.

Even more than the original Tech Act, the Tech Act of 1994 impressed upon the states the need for major systemic change. It focused states' activities on six priority areas to strengthen systems change and advocacy efforts. The most important of these emphasized the coordination of activities among state agencies, the development and implementation of strategies to empower individuals with disabilities, the increase of outreach to underrepresented populations and the creation of strategies to ensure timely acquisition of AT.

The problem with the approach [in the original act] was that the Tech Act didn't have authority over such public funding sources as the Division of Vocational Rehabilitation Services but only over its Tech Act projects. [The states] would work with public agencies and suggest changes to create more access to AT, but there really was no legal obligation from them to do so. The Tech Act lacked any teeth, unlike the Americans with Disabilities Act and the Rehabilitation Act, which set forth specific requirements for agencies dealing with clients who have disabilities.

In 1998, Congress repealed the Tech Act and replaced it with the Assistive Technology Act of 1998 ("AT Act"). "There was a recognition that the provision of assistive technology for individuals with disabilities was not so simple," Bailey noted. In justifying passage of the new law, Congress admitted that the state programs were failing to reach many of their goals. The law notes that state programs were deficient in some core areas, including providing sufficient resources to pay for AT devices and services; providing personnel trained in AT; disseminating information about the availability and benefit of AT; and altering systems to ensure that consumers were getting the AT devices and services they needed when they needed them.

The AT Act made some minor improvements over the provisions of the original Tech Act. For instance, the law reduced the six required activities to four: public awareness, interagency coordination, technical assistance and training and outreach. In addition, the law created discretionary activities that state programs could perform with AT Act funds, such as alternative financing systems to increase AT access.

These minor adjustments are overshadowed by the new law's larger deficits. The AT Act, like the Tech Act before it, contains only nominal enforcement provisions. If a state fails to comply with corrective action, then it is subject to sanctions from partial or complete loss of funding, redesignation of the lead agency or exclusion from the grant process the following year. However, the most serious concern about the AT Act lies in its funding scheme. While the AT Act continues funding for state assistive technology programs and extends funding for some states up to 13 years, it severs all state funding after fiscal year 2004. The AT Act's sunset

continued on page 52

Changing Lives Forever

The Anne Carlsen Center for Children offers a 60-year tradition of residential, therapeutic and educational services on one campus. Our individualized services include care for children and young adults coping with cerebral palsy; orthopedic, vision and hearing impairments; autism, pervasive and other developmental disorders; and many other medical challenges. Our multidisciplinary team can reach out to you by conducting evaluations in your child's home and school setting.

Anne Carlsen Center for Children
Changing lives forever

Jamestown, North Dakota
Call 1-800-568-5175 or visit our
web site at: annecenter.org

Circle #20 or visit www.eparent.com/adinfo

continued from page 51

clause effectively eliminates 23 states from the grant program before the Act is due for reauthorization.

Without continued funding to implement its goals, experts believe there is little hope of the grand systemic change the AT Act promised. According to Bailey, the AT Act "doesn't allow for permanent sustained funding to ensure access to assistive technology devices and services for individuals on a state and local level. It doesn't ensure that systems change efforts and capacity-building activities will continue. These are the activities that are not likely to be funded by state legislatures."

The Association of Tech Act Projects notes another factor not considered by the law's current funding formula: the number of individuals needing access to alternative resources to pay for assistive technology will increase as welfare reform legislation decreases the number of persons eligible for public program supports. Thus, when even more people with disabilities need assistance to access and use AT, the federal government is cutting off all funds to states to provide this service.

In response to the impending shutoff of federal funds for AT projects, some states have taken action. In Illinois, victims of violent crime can receive compensation from the state for the purchase of assistive technology devices and services. In Kentucky, state legislation established the Assistive Technology Loan Corporation, which provides a resource of low interest loans to consumers to purchase assistive technology. And in Missouri, a state law created an equipment distribution program that provides adaptive devices such as text telephones, amplifiers, telebraillers and hands-free phones to individuals with disabilities. New Jersey has yet to commit state legislation or state dollars to assistive technology for its citizens with disabilities. EP

EDITOR'S NOTE: On January 10, 2002, HR 3061 became Public Law 107-116, making appropriations for the Departments of Labor, Health and Human Services and Education for FY 2002. It provides funding for one-year extensions to existing programs under the AT Act, then phases out federal contributions over a three-year period.

Laura Noble is a writer for People with Disabilities Magazine and the mother of a child with special needs.

Reprinted from the September 2001 issue of *People with Disabilities Magazine*, published by the New Jersey Developmental Disabilities Council, by permission of the NJDDC.

Never in my Wildest dreams...

"WHEN I FIRST CAME TO CROTCHED MOUNTAIN OVER 10 YEARS AGO, activities that were second nature prior to the automobile accident were challenging tasks. Today I am a college graduate and also have my drivers license.

Never in my wildest dreams would I have been able to do half of what I've achieved without the encouragement and help that I received at Crotched Mountain! I want to thank everyone at Crotched Mountain for helping me get my life back!"

—Brent Reagan '93
Crotched Mountain School

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call 800-966-2672
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@cmf.org

CROTCHED MOUNTAIN
OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #29 or visit www.eparent.com/adinfo

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

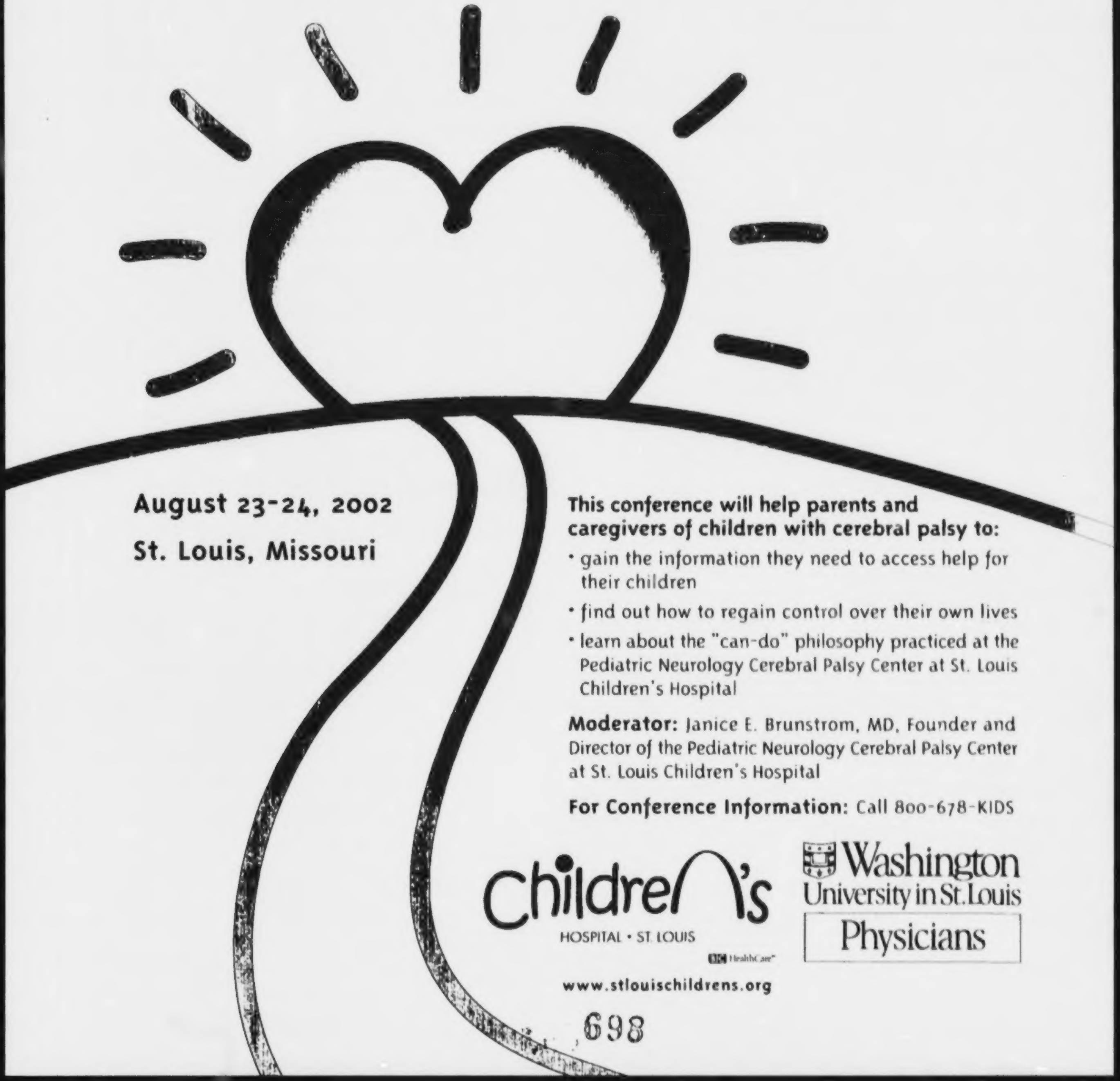
Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #48 or visit www.eparent.com/adinfo

Building
The Road to
Independence

A Conference for Families of Children with Cerebral Palsy



August 23-24, 2002

St. Louis, Missouri

This conference will help parents and caregivers of children with cerebral palsy to:

- gain the information they need to access help for their children
- find out how to regain control over their own lives
- learn about the "can-do" philosophy practiced at the Pediatric Neurology Cerebral Palsy Center at St. Louis Children's Hospital

Moderator: Janice E. Brunstrom, MD, Founder and Director of the Pediatric Neurology Cerebral Palsy Center at St. Louis Children's Hospital

For Conference Information: Call 800-678-KIDS

Children's
HOSPITAL • ST. LOUIS
BJC HealthCare

Washington
University in St. Louis
Physicians

www.stlouischildrens.org

Where can I learn about computer technology that might benefit my child?

by Sheryl Burgstahler, PhD

EP is honored to announce a new monthly column contributed by Dr. Sheryl Burgstahler, director of the DO-IT program. DO-IT (Disabilities, Opportunities, Internetworking, and Technology) began in 1992 with a grant from the National Science Foundation. Funded by the US Dept. of Education, the State of Washington and many other organizations, DO-IT serves to empower young people with disabilities as they transition to college and careers through the use of computers, assistive technology and the Internet. In addition to her role at DO-IT, Dr. Burgstahler is also the assistant director of information systems, computing and communications, the co-director of AccessIT; and the director of the adaptive technology Lab, all at the University of Washington. "Tech Talk" will address practical ways to integrate technology into educational, work and home environments. Dr. Burgstahler will also endeavor to answer readers questions through this column. (Send correspondence to: Dr. Burgstahler, University of Washington, Box 354842 Seattle, WA 98195; fax: (206) 221-4171; e-mail:sherylb@u.washington.edu.

Years ago, we had too little information and too few products that could help children with disabilities gain all of the benefits that computers have to offer. We hear about how assistive technology can level the playing field, but what if you are just getting started? Where can you learn about what is out there? The Internet provides a wealth of information about technology, and specifically about technology for people with disabilities. Here are some of my favorite Web sites:

The Adaptive Technology Resource Center
http://www.utoronto.ca/atrc

Sponsored by the Resource Centre for Academic Technology of the University of Toronto, the site provides information on upcoming workshops, current and completed research projects on assistive technologies and access to the the ATRC library. Also housed by the site is a technical glossary that explains various assistive technology products and provides questions to consider when purchasing them. Information on resource center drop-in hours, employment accommodation services, and instruction on inclusive Web design is also available.

Technical Assistance Project of RESNA
http://www.resna.org/taproject/index.html

RESNA's (Rehabilitation Engineering and Assistive Technology Society of North America) Technical Assistance Project site includes contact information for 56 assistive technology programs in each state and territory. It also contains information on policy changes and emerging initiatives in community living, education, employment, healthcare and telecommunications/information technology. The program also provides access to a library consisting of laws, federal reports and budgets, international reports, congressional hearings, statistics, training materials, and other resources.

Center for Applied Special Technology (CAST)
http://www.cast.org

Furnishes information pertaining to the Universal Design for Learning (UDL), including theories, research, tools, resources, examples, and activities related to UDL. Also available is information on the National Center on Accessing the General Curriculum (established by CAST and the US Department of Education's Office of Special Programs) and descriptions of CAST products such as the Cast eReader and the web based program Bobby. Specialized tours of the site are also accessible.

Closing the Gap
http://www.closingthegap.com/

This site allows access to Closing the Gap's newspaper and a searchable resource directory (published every spring) which highlights a featured product of the week and contact information for supportive organizations.. Closing the Gap also sponsors online forums on the site, which discuss announcements, polls, articles, education and assistive technology practices and strategies, while also making archived discussions available for review.

continued on page 56

[illegible] 699

Connetquot West, Inc.
Health Care Products

Mobility • Bathroom Safety • Specialty Seating
Beds/Patient Rooms/Lifts • Nutritional/Enteral
Respiratory • Diabetic Supplies • Ambulatory

Home Delivery!

Providing the Nation with Top Quality Service & Healthcare Products at Competitive Prices

Incontinence/Underpads • Urological • Skin Care
Pressure Management • Wound Care • Personal Care
Diagnostics • Exam/Treatment • Protective Apparel

For more information, please call
Toll-Free: 866-588-3888
Fax: 866-588-3337
Email: connetquot@aol.com
711-3 Koehler Avenue • Ronkonkoma
New York • 11779

Circle #27 or visit www.eparent.com/adinfo

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #64 or visit www.eparent.com/adinfo

continued from page 55

DO-IT
http://www.washington.edu/doit/

This Washington University site delivers resources on how technology can aid in college and careers for students with disabilities, their advocates, educators and their administrators, in addition to supplying information for K-12 educators. Furthermore, it allows access to information on programs hosted by DO-IT and a link to AccessIT (the National Center on Accessible Information Technology in Education).

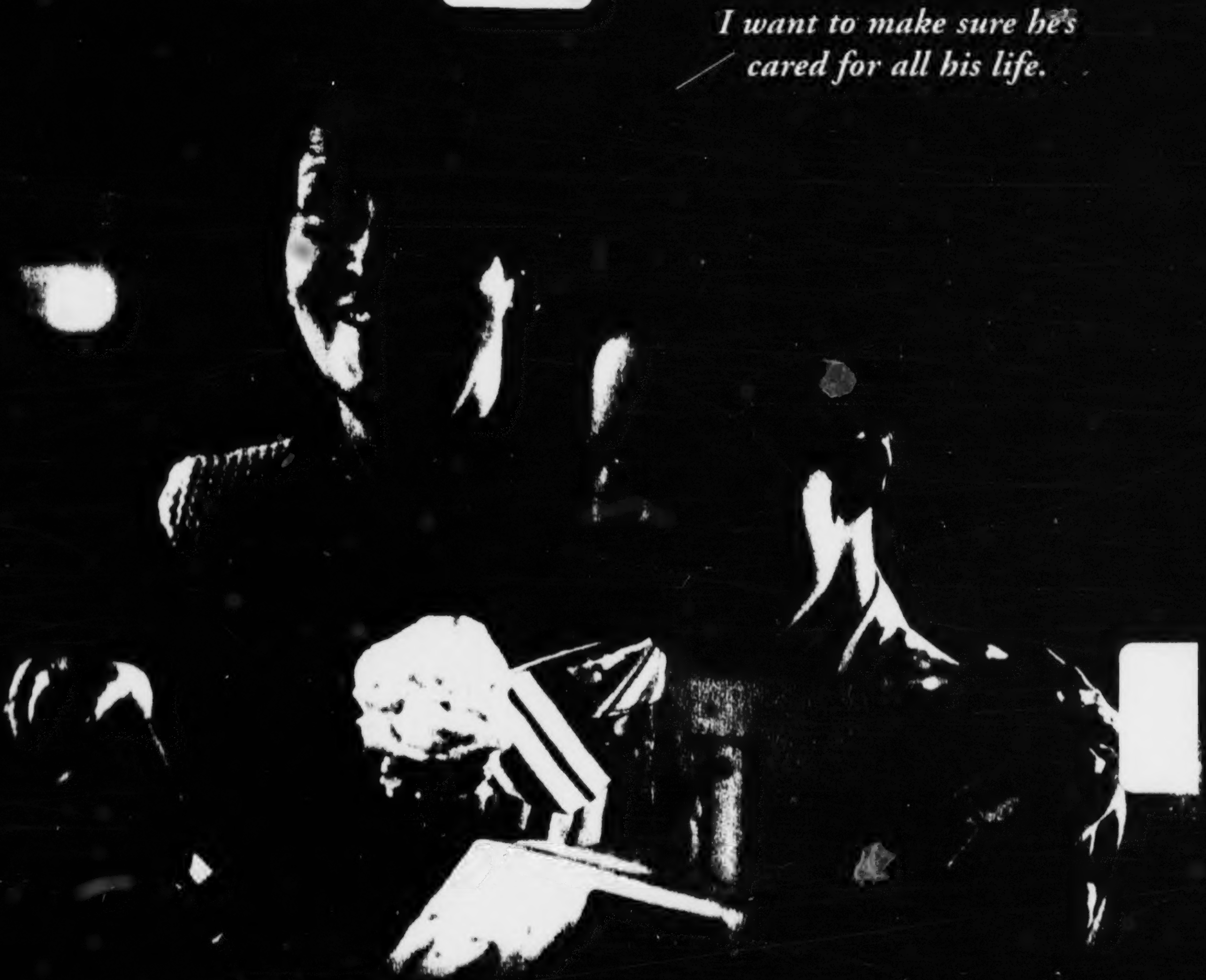
Equal Access to Software and Information (EASI)
http://www.isc.rit.edu/~easi/

EASI provides online training on adaptive technology and how institutions can provide barrier-free computer and information technology systems for persons with disabilities. To aid in this, EASI supplies a "starter kit" for on-line starter kit as well as a web-design kit that provides pointers on designing fully accessible pages. Additional information is available through links to resources in adaptive hardware and software, EASI publications and 13 libraries. The site also includes details on distance learning and legislation and affords online discussions through the EASI network.

The National Center on Accessible Information Technology in Education
http://www.washington.edu/accessit/

This young site (sponsored by the University of Washington and the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education) contains a searchable knowledge base to answer common questions regarding accessible information technology in education. Information on upcoming training activities and events that might be of interest to those who want to learn about or share information about accessible electronic and information technology in education is also provided. Links to case studies and promising practices are also furnished.

There are also hundreds of interactive discussion lists parents can join. Many are organized around different types of disabilities, for example, to share ideas, concerns, and resources with parents of children with hearing impairments, with cerebral palsy or with developmental disabilities. If you have the topic, there is probably a list of people with the same interest out there on the 'Net. For a comprehensive list of Web sites and discussion lists, consult the publication, Disability-Related Resources on the Internet which can be found at http://www.washington.edu/doit/Brochures/DRR/. EP


I want to make sure he's cared for all his life.

I'm Sarah, 43.
My son Jeremy has overcome many obstacles
Financial insecurity shouldn't be one of them.

MetDESK

My husband Bob and I want to make sure Jeremy is provided for when we're not around any more. So we talked to MetLife. Their MetDESK (Division of Estate Planning for Special Kids) specialists helped us with the many financial and legal issues in providing quality lifetime care for Jeremy. Since many of the MetDESK specialists are parents of children with special needs, they're knowledgeable and understand families like mine.

For more information on MetDESK call 1-877-MetDESK (1-877-638-3375). Ask for our brochure *Planning for Your Child with Special Needs* or visit our web site at www.metlife.com/desk.

GET MET. IT PAYS.®

MetLife
Financial Services

PEANUTS© United Feature Syndicate, Inc. Metropolitan Life Insurance Company L00124ROY(exp1205)MLIC-LD
Circle #53 or visit www.eparent.com/adinfo

MANAGEMENT AND CONTROL OF REFRACTORY SEIZURES IN THE MR/DD POPULATION

by Fern R. Potvin, MPA

It has been estimated that almost six million people in the United States have epilepsy and approximately the same number have mental retardation or developmental disabilities (MR/DD). About 25 percent of people with MR/DD also have epilepsy, so it can be assumed that some 1.4 million people have both disorders. Additionally, there is a high level of comorbidity of epilepsy and depression. Yet a significant number of professionals have experience in managing epilepsy, MR/DD or depression only. Moreover, many of the older drugs used to control seizures can have side effects that interfere with cognitive processes and arriving at the right dosage level for both antiepileptic drugs (AEDs) and antidepressants can be a problem.

To ameliorate some of the knowledge gaps, the Exceptional Parent Foundation for Education, Inc. (EPFE), a 501(c)3 non-profit organization, sponsored one-day conferences in January, February and March 2002 in Woodcliff Lake, NJ, Nashville, TN and Los Angeles, CA respectively. Co-sponsors were the Epilepsy Foundation of New Jersey, the Epilepsy Foundation of Southeast Tennessee and the Epilepsy Foundation of Los Angeles, Ventura, San Bernardino and Orange Counties. Designed to offer information on cross-management of these comorbid disorders and provide an update of current therapeutic modalities for epilepsy, the seminar audiences included professionals, parents, families and people with epilepsy and one or both of the other disorders. All three conferences were approved for Continuing Medical Education (CME) credit and for Continuing Education Units (CEUs) in nursing and other medically-related specialties. The conferences were partially underwritten by an unrestricted educational grant from Cyberonics, Inc.

All the seminars followed the same basic curriculum, and the speakers brought their own experiences and viewpoints to bear on their presentations. The faculty roster included neurologists, pediatricians, developmental physicians, epileptologists, a psychiatrist, an internist, parents and community activists.

KEYNOTE SESSIONS

Keynote speakers, renowned neurologists and epileptologists provided an update on neurology in general and epilepsy in particular. They provided an overview of, and commentary on, ongoing research. The history, diagnosis and management of epilepsy were covered, as were types of seizures. The keynotes set the stage for the in-depth presentations that followed.

THERAPEUTIC STRATEGIES FOR REFRACTORY SEIZURES: ANTIEPILEPTIC DRUGS (AEDs)

The use of medication to control seizures has a long history in the United States, as shown in the table below. The table also includes common side effects.

Many people benefit from use of these drugs, either alone (monotherapy) or in combination (polytherapy); the results can be significant abatement of seizures or, occasionally, complete control. Unfortunately, as can be seen from the table, the price of control is almost always sedation, usually resulting in reduced cognitive function. This problem is exacerbated in people with MR/DD.

Attendees at the first seminar in NJ chat with presenter Dr. Russell Joffee during a break.

Moreover, the effects of AEDs diminish over time. This may call for discontinuing a drug and replacing it, or adding a second or third—or sixth or seventh—to the mix. Research has shown that approximately 47 percent of people with epilepsy will be seizure-free with one AED. Adding a second drug will benefit an additional 13 percent, and the seizures of an additional 4 percent will be controlled with the addition of a third AED. Adding still more drugs to the regimen results in almost zero incremental value. Thus, 36 percent of people with epilepsy ultimately do not achieve seizure control with medication, and are said to have refractory, or intractable, seizures.

THERAPEUTIC STRATEGIES FOR REFRACTORY SEIZURES: KETOGENIC DIET, SURGERY

The ketogenic diet can be very effective in children, usually until they are about 6 years old. It is an extremely restrictive regimen of high protein, high fat and very low carbohydrates, and requires absolute compliance. It can be helpful for a limited population for a short time, but is nearly impossible to adhere to for an extended period.

People with epilepsy who are considering surgery must be evaluated to see if they are good candidates for the procedure. First they go through a mapping process, to determine where the centers of epilepsy activity are located within the brain. This may involve electroencephalograms (EEGs), MRI scans, PET scans and the use of electrodes to pinpoint activity. If the person with epilepsy is found to have a localized center of activity, that center can usually be surgically removed and the epilepsy is cured. In the event that activity loci are found throughout the brain, however, surgery is not usually an option.

CHEMICAL NAME	BRAND NAMES	INTRO	SEIZURE TYPE	SIDE EFFECTS
phenobarbital		1912	generalized, partial	sedation
phenytoin	Dilantin	1938	generalized, partial	sedation, dizziness, rash
ethosuximide	Zarontin	1960	childhood absence	sedation
carbamazepine	Tegretol, Trileptal, Carbatrol	1974	partial onset	sedation, dizziness, hepatic damage
clonazepam	Klonopin	1975	adjunct—any type	sedation, tolerance, withdrawal
valproic acid	Depakote, Depakene	1978	generalized	GI, some hepatic failure
felbamate	Felbatol	1993	Lennox-Gastaut; adjunct for generalized, partial	bone-marrow, hepatic failure
gabapentin	Neurontin	1993	adjunct—partial	sedation, drowsiness, dizziness
lamotrigine	Lamictal	1994	generalized, partial	rash, sometimes Stevens-Johnson syndrome
topiramate	Topamax	1996	generalized, partial, Lennox-Gastaut	sedation, somnolence, cognitive dysfunction
tiagabine	Gabitril	1997	adjunct—partial	dizziness, tiredness
levetiracetam	Keppra	1999	adjunct—partial onset	somnolence
zonisamide	Zonegran	2000	adjunct—partial onset	somnolence, renal calculi

In young children, more extensive surgery might be performed. As much as half of the brain can be removed in a procedure called a hemispherectomy and, because of the plasticity of the child's brain, the remainder can take over the functions normally handled by the resected areas.

MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

People with MR/DD and epilepsy, their parents and families and the professionals who provide their care and treatment are presented with a dual challenge. Compliance with a drug regimen can be hard to maintain, depending on the person's cognitive limitations. Ability to describe how they feel during or after seizures can be limited not only by cognition but by difficulties in communication. Parents and professionals become frustrated by their inability to control or eliminate the seizures and make the person comfortable; they may also be distressed by their inability to explain what's happening to the person having seizures.

The situation is compounded by the drugs themselves. Sedation, dizziness or somnolence are likely to diminish any individual's ability to function optimally. For a person who has cognitive limitations to begin with, the effect of sedating drugs is multiplied. Early intervention programs and ongoing work have enabled many people with developmental disabilities to achieve at far higher levels than might have originally been expected, but are unlikely to be successful with children who are highly sedated.

The impact of epilepsy on people with MR/DD is far more than seizures, falling or discomfort from non-cognitive side effects, as unpleasant as they all are. The outcome of constant sedation is likely to result in a significant diminution in their ability to learn, to master skills, to stretch and grow and achieve their potential.

DEPRESSION

Depression is a result of biochemical imbalances within the body; it is thought that there is a genetic component to depression, but this has not yet been proven. As much as 20 percent of the US population—56 million people—will have at least one depressive episode during their lives; a smaller number will have recurring or chronic depression. Drugs and talk therapy are both successful treatments for depressive episodes. Ongoing drug therapy for chronic depression, however, is subject to the same trial-and-error process as ongoing drug therapy for epilepsy; ultimately, some people receive no benefit at all from medication and are considered to have chronic refractory depression.

In treating people with depression and epilepsy, the professionals involved must be aware of all medications each person is taking. Interactions between some antidepressants and some antiepileptics can have serious, and sometimes fatal, consequences.

COMMUNITY OUTREACH

People with epilepsy, even those who also have MR/DD and/or depression, do not live in a hermetically-sealed capsule hidden away from the world; they are residents of at least one community and possibly of many. There's the community of actual residence, which might be a residential facility or a group home, the parents' home or an independent apartment or a college dormitory. This is set within the context of the "local community" of the neighborhood or borough or town. There are communities of faith, communities of ethnic and cultural heritage, communities of workers in the same field or the same company, communities of sports fans and opera fans, scrapbookers, stamp collectors, gardeners and golfers. The community-based workers, advocates and parents who spoke at the three conferences described ongoing programs to support people in these different communities, to enhance their awareness of one another and newer, broader ones that would enable them to serve more people.

MANAGING REFRACTORY SEIZURES IN THE MR/DD POPULATION

Each conference explored one additional therapeutic modality for the management of refractory seizures, the Vagal Nerve Stimulator (VNS). This device was approved by the FDA in 1997 and has been implanted in 15,000 people to date. Yet it is still relatively new and gen-

continued on page 60

FACULTY

Martina Bebin, MD
Associate Professor of Pediatrics and Neurology University of Alabama at Birmingham, Birmingham, AL

Orrin Devinsky, MD
Professor of Neurology, Psychiatry and Neurosurgery NYU School of Medicine; New York, NY

Jacqueline A. French, MD
Professor of Neurology University of Pennsylvania School of Medicine; Philadelphia, PA

Lupe Gonzalez;
Program Staff Epilepsy Foundation of Los Angeles, Ventura, San Bernardino and Orange Counties Los Angeles, CA

Ada Dot Hayes, MD
Consulting Developmental Pediatrician Tennessee Department of Mental Retardation; Nashville, TN

Sandra L. Helmers, MD
Associate Professor of Neurology Emory University School of Medicine Atlanta, GA

Melinda L. Hickey
Director, Programs and Services Epilepsy Foundation of Southeast TN; Chattanooga, TN

Roger L. Huf, MD
Assistant Clinical Professor of Pediatric Neurology UCLA School of Medicine Los Angeles, CA

Russell T. Joffe, MD
Dean and Professor of Psychiatry New Jersey Medical School University of Medicine and Dentistry of New Jersey Newark, NJ

Theodore A Kastner, MD, MS
Associate Professor of Clinical Pediatrics, New Jersey Medical School University of Medicine and Dentistry of NewJersey; Newark, NJ

Seth M Keller, MD
Neurology Consultants of Burlington County, PA; Lumberton, NJ

Marcelo E. Lancman, MD
Assistant Professor of Neurology New York Medical College Valhalla, NY

Philip B. May, Jr., MD
Director, Developmental Medicine Program; Brunswick, NJ

Frank J. Murphy, Jr.
President and CEO; EP Foundation for Education, Inc. Atlanta, GA

Nancy A. Niparko, MD
Clinical Instructor, UCLA School of Medicine; Los Angeles, CA

Michael Painter, MD;
Professor of Neurology University of Pittsburgh School of Medicine; Pittsburgh,PA

Rick Rader, MD
Director, Morton J. Kent Habilitation Center at Orange Grove Chattanooga, TN Editor-in-Chief, EP Magazine

W. Donald Shields,MD
Director of Adult Neurology Westchester Institute for Human Development/UAP; Valhalla, NY

Joseph M. Valenzano, Jr.
President, CEO and Publisher EP Communications River Edge, NJ

Angus A. Wilfong, MD, FRCPC
Assistant Professor, Pediatrics and Neurology Baylor College of Medicine Houston, TX

continued from page 59

erally unfamiliar to many professionals, people with epilepsy and their families.

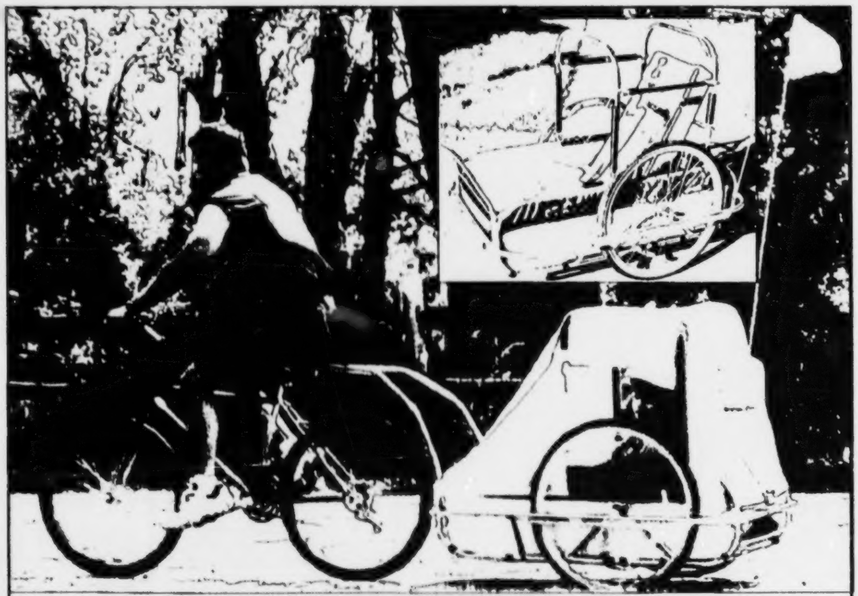
The VNS is similar to a pacemaker. The device is implanted in the chest and wires with electronic stimulators extended under the skin to the left vagus nerve in the neck. The device stimulates the left vagus nerve on a preprogrammed cycle; the stimulation generally reduces the frequency and severity of seizures. Swiping a magnetic wand across the chest over the implant can forestall or interrupt a seizure. Some people with the implant have gone from, for example, 60 seizures a month to one a month; some have become completely seizure-free; others (a small minority) have seen no real improvement and have had the device removed. Many people with the VNS have been able to stop taking any AEDs; others have been able to reduce both the number of different drugs and the dosages.

The predominant side effect of the device is short-term hoarseness. If it continues, the VNS cycle can be readjusted slightly. Some people have not been able to tolerate the feeling of the device cycling, while others have found it to be ineffective. The implant can be removed without long-term effects.

The VNS offers real options for controlling refractory seizures in people with developmental disabilities and has the potential to improve their quality of life significantly. The most obvious is the potential to reduce dramatically the number, strength and duration of their seizures. Second, if they have been taking AEDs that can cause hepatic failure or other potentially fatal consequences, stopping the medication can significantly reduce their long-term risk. Third, and particularly important, they will no longer be subject to the constant sedation and dizziness caused by the drugs. The combination of increased alertness and feeling well physically can allow people with MR/DD to reach their maximum potential in all areas of life.

MANAGING REFRACTORY SEIZURES IN PEOPLE WITH DEPRESSION: INVESTIGATIONAL ONLY

Many people with intractable epilepsy also have chronic refractory depression. Early reports from people in this group indicated that not only had their seizures abated, but



Enjoy the out-of-doors together with a

CycleTote® Bicycle Trailer Running Stroller

1-800-747-2407 www.cycletote.com

Satisfaction Guarantee/Lifetime Warranty

their depression had lessened. As the anecdotal evidence increased, several researchers began studies on use of VNS for refractory seizures and depression and on refractory depression alone. Much work is still to be done, but the outcomes seem to be positive and research continues.

All three conferences included an active question-and-answer period, and attendees were particularly pleased to have an opportunity to follow up on points raised during the sessions.

CLOSING REMARKS

Rick Rader, MD, is the director of the Morton J. Kent Habilitation Center at Orange Grove Center in Chattanooga, TN and the editor-in-chief of EP (EXCEPTIONAL PARENT). This is an excerpt from his talk at the end of each conference.

"The effective and definitive treatment of epilepsy has eluded physicians since at least 25 BC, when it was suggested that 'some have freed themselves from such a disease by drinking the hot blood from the cut throat of a gladiator; a miserable aid made tolerable by a malady still more miserable.' Today's generation of AEDs, coupled with Buck Rogers-like implantable brain governors, has given new hope to families impacted by epilepsy and developmental disabilities. The ultimate goal, of course, is in the future: the prevention and cure of epilepsy. There will be no seizures and no side effects for those who have already developed the condition, and dramatic new ways of preventing epilepsy that results from injury, infection, or errors of brain development. Yet these lofty visions are chimeras for the more than one million people who suffer continuing seizures despite the array of treatment options. Coupled with new treatment modalities, the best strategy is still the vigilance and support of parents, families, teachers and direct support professionals."

In summing up the three conferences, Frank J. Murphy, president and CEO of EPFE, noted that, "It was encouraging to see all the enthusiasm on the faces of the parents and families in attendance. The presenters were excellent communicators and offered the attendees much needed new information." EP

Get More Out of Vestibular Stimulation with The Motion Table

The Motion Table enables therapists to deliver the value of vestibular motion to their patients without the need for constant hands-on intervention.

Most stimulation equipment available today reduces the therapeutic effect of *horizontal motion* by incorporating rounding, swinging and tilting motions. **The Motion Table**, through its smooth, "vibra glide" movement provides a steady, uniform stimulation that can help "level out" extremes in patients' behavior.

And, since **The Motion Table** is motorized, patients can be stimulated for longer periods than is possible with manual equipment.

The Motion Table comes in several sizes and is available from RedBarn Enterprises, a leader in innovative solutions for therapists and their patients.

The Motion Table reduces...
- *Hypersensitivity*
- *Self-abuse*
- *Abnormal Muscle Tone*
- *Constipation*
- *Pulmonary Congestion*

The Motion Table increases...
- *Concentration*
- *Attentiveness*
- *Calmness*
- *Body Awareness*
- *Postural Control and Balance*

RedBarn ENTERPRISES

Try The Motion Table AT NO RISK for 30 days.
Try it for a month. If you're not completely satisfied, just send it back for a complete refund.

For a copy of a just-released Technical Evaluation of The Motion Table or additional product information, call us at 1-800-577-1317, or visit us on the Worldwide Web at www.redbarn-enter.com.

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.redbarn-enter.com**

Circle #57 or visit www.eparent.com/adinfo

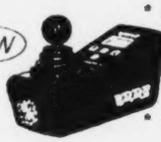
The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW



- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made In U.S.A.

Circle #40 or visit www.eparent.com/adinfo

Women and Epilepsy: Breakthrough Seizures

by Cynthia L. Harden, MD

Dear Doctor:
Our daughter has refractory seizures and autism. We have been keeping data on her seizures for the past 10 years, and know that her seizures are more frequent during her times of ovulation and menstruation. We have heard of progesterone therapy for women such as she. Can you give us more information?

Dr. Harden responds:
Yes, you are correct; progesterone has been used to treat seizures that occur relative to the menstrual cycle. Catamenial seizures, also called catamenial epilepsy, occur in about one-third of all women with epilepsy. Women who have refractory complex partial seizures or generalized tonic clonic seizures are most likely to experience catamenial exacerbation, which occurs most commonly at the time of menstruation. Less often, catamenial seizures may arise at the time of ovulation or may last from ovulation to the beginning of menstruation.

In laboratory research, progesterone, in both its natural form and synthetically made (medroxyprogesterone), has strong antiseizure properties. The metabolites of natural progesterone have powerful effects on enhancing gamma-amino-butyric acid (GABA) activity in the brain. GABA is an inhibitory neurotransmitter and therefore increasing its activity would be expected to decrease the likelihood of seizures.

Progesterone, when used in women with epilepsy to prevent seizures, must be considered a complementary and unproven treatment, used only in combination with standard antiseizure treatments. It does not appear to be a powerful-enough treatment to be used alone. Further, it must be kept in mind that hormonal changes only influence seizure occurrence, and menstrual hormonal cycling is not the underlying cause of seizures. Whether using a hormone such as progesterone can prevent these hormonally-influenced seizures remains to be proven.

At this time, the National Institutes of Health has sponsored the first clinical trial of this complementary treatment for epilepsy, using natural progesterone to treat seizures in women with epilepsy. It is underway at the Harvard Neuroendocrine Unit of Beth Israel Deaconess Medical Center, Boston; Weill Cornell Medical Center, New York City; Thomas Jefferson Medical Center, Philadelphia; and Emory University School of Medicine, Atlanta. In the study, natural progesterone is used as it has been in previous small clinical trials, taken three times a day during the second half of the menstrual cycle (luteal phase), from ovulation until the onset of menses. In clinical practice, the prescription form of natural progesterone called Prometrium™ is used at fairly high doses during the luteal phase, as additional therapy to standard antiseizure treatments.

This intermittent method requires that menses are fairly regular, so the starting date of progesterone therapy can be scheduled. Natural progesterone is tapered off over 2 to 3 days after menses start, not stopped abruptly. Some women experience an improvement in their catamenial seizures with this approach. Side effects can include sedation, fatigue, irritability, depressed mood, breast tenderness and premature onset of menstrual bleeding if progesterone is begun too early in the cycle. A gynecologist should be consulted prior to starting progesterone treatment to ensure that hormonal use is safe for the individual.

Synthetic progesterone in the form of Depo-Provera™ has also been used with some success, given at higher doses than those used for birth control. The beneficial effect on seizures with Depo-Provera is most striking if it blocks menstrual cycling altogether. Therefore, Depo-Provera as a treatment for epilepsy also requires the guidance of a gynecologist as well as a neurologist.

Progesterone is a potentially beneficial complementary treatment for seizure disorders in women who have seizure exacerbations in relationship to their menstrual cycles. Its exact benefit remains to be proven and is currently under evaluation. The neurologist and gynecologist should both be involved when progesterone is used for women with epilepsy. EP

Cynthia L. Harden, MD, is Associate Professor of Neurology and Neuroscience and Associate Attending in Neurology at the Weill Medical College of Cornell University in New York, NY. Dr. Harden is a member of several professional societies including the American Epilepsy Society and the American Academy of Neurology, where she is an officer in the Epilepsy Section. She chairs two committees of the American Epilepsy Society: the Task Force for Women with Epilepsy and the Focus Group for Women Working in Epilepsy. She has received numerous honors and awards and has been a speaker at more than 60 symposia and invited lectures.

Ask the Doctor addresses issues of concern to our readers. Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products. Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com.

706

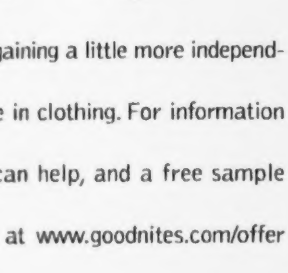
WHY CHILDREN WHO RELY ON GOODNITES ARE MORE INDEPENDENT.

Independence means different things to different people. For children with bladder or bowel control problems, it could just mean getting through the day dry. That's why something as simple as a change in clothing, can, even in a small way, change a child's way of life.

GoodNites® absorbent underpants can help a child become more independent. With GoodNites, accidents won't become catastrophes. So your child will be able to do more. Plus, because they look like real underwear, kids don't mind wearing them. And since they're easy to pull on and off, they can make a child feel more self-reliant.

GoodNites are available in 3 sizes: 45–65 lbs., 65–85 lbs., and 85–125 lbs. That means finding the size that fits your child will no longer be a problem. Plus they have tear-away sides and they're latex-free.

- *Day and nighttime protection*
- *Latex-free*
- *Tear-away sides for easy removal*
- *Three sizes, to fit kids from 45–125 lbs.*



Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS
45 lb & over

For Better Days.

Imagine your child gaining a little more independence just by a change in clothing. For information on how GoodNites can help, and a free sample offer, please visit us at www.goodnites.com/offer

®Registered trademark of Kimberly-Clark Corporation. ©2000 KCC.

BEST COPY AVAILABLE

Circle #75 or visit www.eparent.com/adinfo

NO EXCUSE FOR FAILURE: BILL PORTER, ROLE MODEL

By Joseph M. Valenzano, Jr. and
Natalie Gerber, PhD

An American Hero

By Joseph M. Valenzano, Jr.

Many years ago, I was fortunate to hear Jim Valvano, the late great North Carolina State University basketball coach, deliver a stirring speech that wasn't just another sports tale but a profound lesson about life. Coach Valvano had just led his NC State team to the pinnacle—the championship of the NCAA Tournament. It was arguably the greatest upset victory ever in the history of collegiate basketball.

Coach Valvano talked extensively about his mother and father and how much they meant to him. The coach ended his talk by telling a poignant story. One day, after winning the championship, Jim noticed a suitcase by the bed in his father's room. When he asked him about it, his father explained that his bags were packed and he was ready to go to the next championship game his son coached. Jim Valvano laughed and told him, "Dad, it's hard to do." His father responded, "I know. But you will do it. My bags are packed."

Coach Valvano reflected on what his father said; his father had given him perhaps the greatest gift he ever received. Despite his shortcomings and failures, his father always believed in him. Believing in someone instills a quality of imagination, a sense of courage over timidity that propels people, ordinary people, to accomplish extraordinary things.

Bill Porter and Shelly Brady

On July 14th at 8pm, Turner Broadcasting System will broadcast nationally the TNT original film, *Door to Door*, which tells the story of Bill Porter. Bill is an Oregonian from Portland who became a top-selling salesperson for Watkins Products, the manufacturers of home and personal care goods. Back in 1961, when Bill began his 40-plus-year association with the company, Watkins products were sold door to door. In those days, salespeople like Bill strove to sell $1,000 a month, which would earn them entry into the coveted Watkins $1,000 Club. Within seven months on the job, Bill parleyed his natural passion for sales (his father Ernest was

On occasion we come across a personal story so powerful that we remark on how "life imitates art." But it is very rare for art to depict accurately the lives of people who have disabilities with appropriate portrayals, passion and dignity. Mitch Albom did this admirably in his book *Tuesdays With Morrie*. Maria Shriver accomplished it in her book *Ten Things I Wished I Learned*. This summer our nation will be treated to a book and movie that take these concepts and go one step better.

The book, authored by Shelly Brady, is called *Ten Things I Learned from Bill Porter*. The movie based on the book, entitled *Door to Door*, is a Turner Broadcasting Production starring Academy Award nominee William H. Macy.

I had the privilege of interviewing Shelly and I can tell you that she is a woman of enormous dignity, faith and talent. She is also a devoted mother of six and the kind of friend each of us can only hope to have in our lifetime. Her book captures not only the essence of what it is like to live with a disability but how to succeed and prosper in spite of it. I doubt there was ever a clearer example of how to adapt, improvise and overcome obstacles than Shelly's heart-wrenching depiction of her friend and employer, Bill Porter, a real American hero.

Bill Porter, a man with cerebral palsy, became a door-to-door salesperson. Not just a good salesperson, but one of the best. His life was shaped and nurtured by the resolve, dedication, faith and iron will of his mother, Irene, who—despite the "best medical advice of her time"—simply believed in her beautiful little boy. If she ever had any thoughts about "why did this happen to me?" or "why my little Bill?" my bet is they were only fleeting. She knew there were more important things to do.

She had to get on with the task of being an exceptional parent. She had to help Bill understand that he could achieve anything, that she believed in him and that he needed to believe in himself as well!

I asked Shelly for the best example of Bill's perseverance in the face of overwhelming odds. She told me about the time Bill was out making sales calls during a major ice storm. The storm became so bad that the bus lines Bill relied on for transportation suspended service. He had to hitch a ride home, only to find that the ice was so thick he couldn't walk up his driveway. Instead, he got on his hands and knees and crawled to his front door. When Shelly asked, "Bill, are you crazy going out in a storm like this?" Bill quietly responded, "It's the best time to sell; more people are home at this time."

For those who may ask why God created a boy with all those "imperfections," the answer given in the book is really quite simple. It is because the world.... all of us... needs Bill Porter. We need him to teach us to look at the person first, the disability second, because when you do that, anything is possible. We need Bill Porter to provide us with yet another shining example of what can be done, what can be achieved if we believe in each other.

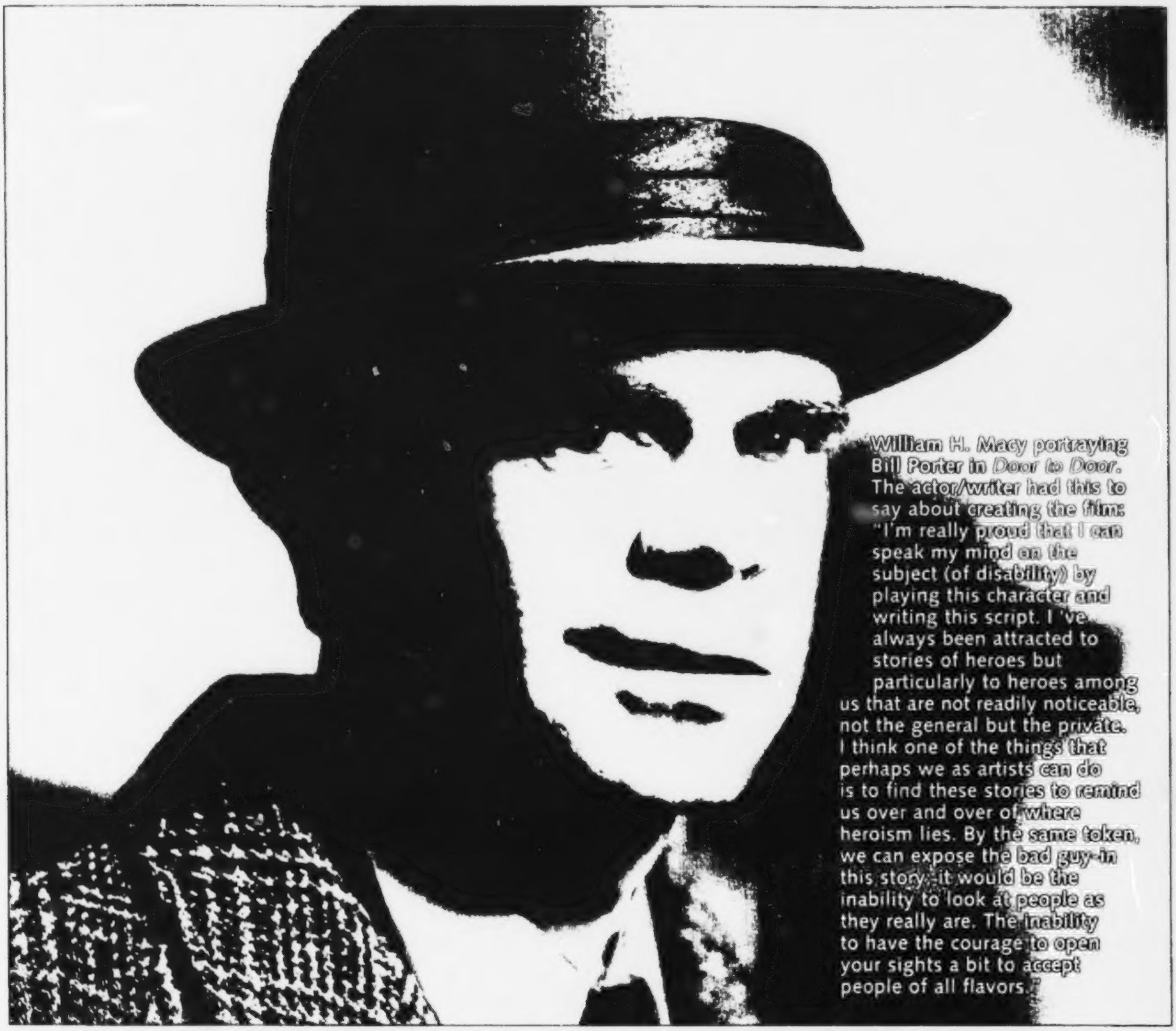
Thank you, Bill. Thank you, Shelly. God bless.

also a salesperson), his positive attitude and his belief in the money-back-guaranteed products he sold into a successful bid for membership in this club. For any young salesperson, such a sudden rise to success would be meteoric. But when you consider that Bill also has cerebral palsy—and had to prove that he was able to do his job, first by accepting the worst territory in Portland and then by working strictly on commission—his success story becomes nothing short of miraculous.

Yet Bill would be the last person to characterize his success in this way. He attributes it instead to his determination to see all situations as sales opportunities. Even when his body ached from seven to ten miles of walking

Bill Porter working on his correspondence

continued on page 66



William H. Macy portraying Bill Porter in *Door to Door*. The actor/writer had this to say about creating the film: "I'm really proud that I can speak my mind on the subject (of disability) by playing this character and writing this script. I 've always been attracted to stories of heroes but particularly to heroes among us that are not readily noticeable, not the general but the private. I think one of the things that perhaps we as artists can do is to find these stories to remind us over and over of where heroism lies. By the same token, we can expose the bad guy-in this story-it would be the inability to look at people as they really are. The inability to have the courage to open your sights a bit to accept people of all flavors."

"Every door that slammed in his face was a door he knew he would someday open."

continued from page 65

a day, Bill says, "motivation...and a responsibility to the customers kept me going. If a door slammed, then I tried a little harder at the next door to persuade them to hear me out!"

Actor William H. Macy, who co-wrote the script for *Door to Door* and stars as Bill Porter, characterizes Bill as an extraordinary person whose stoicism and sense of humor made him a consummate salesperson. As Macy comments, "Bill is a successful salesperson. That's hard to do even if you don't have cerebral palsy. It's rough to do, and he succeeded wildly. He stayed his own man all through his life."

Bill's former delivery assistant and now business partner, Shelly Brady, has portrayed Bill's incredible perseverance in her new book, *Ten Things I Learned from Bill Porter* (New World Library, June 2002); its release roughly coincides with the TNT film broadcast. As she recounts, Bill's success derives from his incredible persistence and perseverance. "Where you or I might be discouraged by a simple 'no,' Bill always heard an eventual 'yes.' Every door that slammed in his face was a door he knew he would someday open."

One telling anecdote in the book captures what truly makes Bill a standout. Several years ago, Bill and Shelly were flying to a speaking

continued on page 68

Johnny, 51 lbs. and 48" tall, in the Columbia Car Seat
Sharing the Caring

Columbia offers you solutions to the daily challenges of transporting, bathing and toileting your child – *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

■ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.–yet weighs only 11 pounds! It has been the No. 1 choice since 1986, for its adjustability and stylish comfort.

#2000 Car Seat

■ At bathtime, our popular **Reclining Chairs** and **Wrap-Around Bath Supports** allow your child – and you – to enjoy the bath.

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

#7700 Hi-Back Wrap-Around Support

■ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.

Why do these products work so well? Columbia products are thoughtfully designed, with each item available in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, tested and proven in real-life experience. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

#4200 Small Support for children

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

COLUMBIA
SHARING THE CARING

BEST COPY AVAILABLE

711

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG

Columbia Medical Mfg. Corp., Dept D1, P.O. Box 633, Pacific Palisades, CA 90272

Visit Our Web Site at http://www.ColumbiaMedical.com

Circle #26 or visit www.eparent.com/adinfo

Helen Mirren and William H. Macy appear as Irene Porter and her son Bill in *Door to Door*, Airing 8 pm EDT July 14th on TNT

continued from page 66

engagement at a sales meeting, something they have done often in the past few years, as many corporations worldwide have asked them to be motivational speakers. But Bill, who had never flown before, did not have a picture ID and was not permitted to board the plane. Shelly and Bill decided to make a quick side trip to the Department of Motor Vehicles, where a friendly DMV worker recognized Bill and quickly—and somewhat liberally—processed an ID for him. While Shelly organized paperwork and felt frazzled, Bill sold his new friend a can of Watkins cinnamon.

It is this ability to turn disappointing circumstances into sales opportunities that has made Bill the top-selling Watkins salesperson in Oregon and the Northwest Region, and among their top ten salespeople in the US. As Shelly says in the book, "Bill Porter is a perfect example of an individual succeeding because he stayed focused on something he felt passionate about."

Remarkably, Bill Porter sees himself as an ordinary person doing a job in order to pay the rent. When asked if he ever thought of himself as a role model, Bill Porter nonchalantly replies, "It didn't really ever cross my mind. I

The Ten Lessons

In *Ten Things I Have Learned From Bill Porter*, Shelly has shared the blessings that she and her family have received from knowing Bill. The book summarizes these in 10 basic points:

1. Follow your passion.
2. It doesn't matter how you got here, only where you're going.
3. Mother knows best.
4. Persistence pays off.
5. Don't take "No" for an answer.
6. Know your limits and reach beyond them.
7. Be a team player.
8. If it isn't broken, don't fix it.
9. There are no obstacles.
10. Live your values.

Ten Things I Learned from
SHELLY BRADY

just went about my everyday job." That everyday job, sales, is recognized as one of the most difficult professions in which to achieve success. Regardless, Bill was never uncertain in his ability. "It's the one thing I felt I could do—no, I knew I could do it!"

Bill credits his mother, Irene, for building confidence in him. "Mom told me I could do anything I set my mind to do. I knew she was behind me all the way. No matter what problems or handicaps you have, you have to go ahead and do your job."

Though he may see nothing extraordinary in his life, others disagree. William H. Macy was drawn to Bill Porter's determination and extraordinary selling ability after viewing ABC's powerful *20/20* program segment about Bill's life, which generated the highest viewer response in the show's history. "One must just stop and imag-

continued on page 70

from Chapter 5:

"Don't Take 'No' for an Answer"

"According to the Merriam-Webster Dictionary, the word 'no' is an act or instance of refusing or denying something. For instance, a customer's refusal to purchase goods or services from a salesperson is generally expressed via the word 'No.' For some reason or another, Bill Porter doesn't hear it that way! Bill hears the word 'no' differently; he hears it to mean that the customer will be glad for Bill to return at a more convenient time or pleased to be shown another, more necessary product...

I learned from Bill Porter that when someone says 'no' they are simply asking you to modify your proposal or change your delivery. I believe that Bill's attitude toward the word 'no' and his ability to not focus on the 'negative' are traits that many people admire in him.

Some have interpreted Bill's cerebral palsy as one gigantic 'No' dished out by the heavens, but he never looked at it that way... When he could have collected disability or at least taken a job that wasn't so mentally and physically demanding, Bill chose instead a profession—door-to-door sales—that challenged his so-called 'handicap.'"

From *Ten Things I Learned from Bill Porter.* Copyright © 2002 by Shelly Brady. Reprinted with permission of New World Library, Novato, CA. www.newworldlibrary.com. Toll-free 800/972-6657 ext. 52.

Custom Made With Love

Everyone is different. Different shapes. Different sizes. Different needs. That's why at Danmar we customize our products for each individual. Seating and positioning devices which fit to a T. Helmets custom-designed for pony tails or buzz cuts. Swim aides so secure you're a fish in the water. You have a special need. We have a special product, one custom made from the heart.

Website: www.danmarproducts.com
Phone: (800) 783-1998

DANMAR

Special Products for special needs since 1968.

Dan mar Products, Inc., 221 Jackson Industrial Drive, Ann Arbor, MI 48103 USA

Circle #31 or visit www.eparent.com/adinfo

What Makes Bill Porter So Special?

EP President, Publisher and CEO Joe Valenzano, Jr. (JV) spoke with Shelly Brady (SB) about Bill Porter's business success and his influence on her life. The interview took place on April 26, 2002 at the United Cerebral Palsy annual national conference in Minneapolis, MN.

JV: How has your view of people with disabilities been shaped by your relationship with Bill Porter?

SB: Knowing Bill has been such a blessing in my life and the life of my family. I was taught from an early age to look beyond outward appearances. My relationship with my friend Bill has been a constant reminder that, no matter what, we are all part of the human family. We may come in different shapes and sizes, different colors, rich or poor, from here or from there...and we may be differently-abled, but we are all brothers and sisters.

JV: Have you ever felt that Bill's disability influenced your relationship?

SB: Not at all. From day one, Bill was my boss. I respected him as my boss....I did see a customer here and there who would come to me and tell me that they purchased something they just didn't need because they wanted to help this "disabled" man and then they would ask me to tell Bill not to come to their house anymore. I would just reply, "It wouldn't matter if I told him not to come to your door. He'll come anyway, and so you had better figure out how to say no. Good luck! And I'll probably see you next time when I deliver your next order!" To me, Bill is not a man with a disability. Bill is, well, Bill!

When I was in high school I thought it was so cool that I worked for a man who had some sort of 'handicap' (I didn't know at the time that he had CP), yet he was so successful. I really respected him as my boss. I have had quiet moments, after kissing my six children goodnight and tucking them in, when I have felt bad that Bill never experienced marriage or the joy of being a parent. Then, when they are screaming and at each other's throats, I've just felt sorry for myself!

JV: What lesson has Bill taught your children?

SB: The lesson is that we are all people, all part of this human family, ,and we all need a friend. We need to look beyond our obvious differences to find out what we have in common...Bill has [also] taught them a great deal about valuing work. For several years, my entire family helped to deliver Bill's Watkins products. We saved the money we earned from Bill, and it helped pay for a family trip to Disneyland.

JV: Has knowing Bill had an impact upon your parenting?

SB: I look at how great Bill turned out, and I hear how often he tells me his mother had the greatest influence on his life. I know I want my children to grow up and be such wonderful adults and contribute to society the way Bill has.

JV: Your daughter Katrina has PVNS (pigmented villanodular synovitis, a rare disease that is a recurring benign tumor within the knee joint, causing severe pain and limited mobility). How has your experience as a parent coping with her disability been affected by your relationship with Bill?

SB: It has given me a newfound respect for him and his mother. Our relationship with Bill and some of the new friends we have met at Shriners Childrens Hospital, where Katrina has had three of her five surgeries (and is on the wait list for her sixth), helps to keep things in perspective. Bill is so concerned about Katrina's health and her illness. He can't imagine going through what she is...Of course, we can't imagine going through the obstacles that he has...We are able to keep our perspective and have an appreciation for our own trials.

Photo this page by Lucretia Coley, UCP.

Cover and photos pages 64 & 63 courtesy Shelly Brady.

Photos from *Door to Door* Page 66 Art Streiber, page 68 Chris Large, both ™ & ©2001 TNT.

continued from page 69

ine for a second, hearing a knock at your door, opening it up and having this fellow talk to you," Macy says. "And when the day is done, he sold you $40 worth of stuff. It is not an easy job," he adds. "He just does not think that what he has done with his life is extraordinary, and I most respectfully disagree with that."

Bill takes in stride all of the new attention that the *20/20* segment and now the book and the movie have produced. While he does not seek publicity for himself, he knows better than to turn down an opportunity for sales to new friends and customers. (The end of the movie plugs his Web site, http://www.billporter.com, on which he continues to sell Watkins home and personal care products.) Yet while all the attention has brought him

BEST COPY AVAILABLE

some new financial stability and allowed him to pay off the hospital bills incurred when he was struck by a bus in 1997 (ending his door-to-door sales career), his hopes for the film are directed toward others. "I hope the movie and the book will inspire a lot of people to make the most of their ability," he says.

In particular, Bill is glad that the film has proven so inspirational to the United Cerebral Palsy Foundation (UCP), with whom his mother Irene was deeply involved, and whose products first launched his own sales career. He is enthusiastic about the prerelease screening events that nationwide UCP chapters are hosting and hopes that they will encourage others the way that the UCP once encouraged him and his family. "UCP was a big support for my family when I was first starting out as a salesman," he says, adding thoughtfully, "I feel as though it helped me become independent. I am so glad that, in a small way, I can give back by sharing my story and being involved today. I hope that my story can encourage others and offer support to others the way UCP was there for my family."

"UCP is proud to be associated with *Door to Door*, and celebrates the triumph of the human spirit with the cast and crew," says Paul T. Burke, UCP's director of marketing and communications. "The film reflects an individual's right to work, advocates for full citizenship and honors the true essence of the Americans with Disabilities Act."

Bill has his own words of encouragement for any young person with a disability seeking the dignity of a job and a regular paycheck. "Keep on trying," he says. "Opportunities will come eventually, as they did for me." His words are evidence of the patience and perseverance that have made him such a success in business. "People change their minds when they fully understand," he adds. "Never give up!" EP

Door to Door airs on TNT on July 14th at 8pm EDT (check local listings for the exact time in your area). The all-star cast includes Academy Award nominees William H. Macy (as Bill Porter) and Helen Mirren (as Irene Porter), and Emmy Award-winner Kathy Baker. The script was co-written by Macy and Steven Schachter, who also directs. An estimated 20 million people nationwide are expected to tune in for the broadcast.

Check with your local UCP chapter to see if they are hosting a launch event for the film during June.

Exceptional children deserve exceptional care.

The best help for cerebral palsy, spina bifida and related disorders is at Kennedy Krieger Institute.

For 61 years, Kennedy Krieger Institute has been the leader in helping children with severe disabilities. Focusing on early identification, intervention and treatment, our state-of-the-art interdisciplinary team approach—combined with a caring, supportive touch—has enabled generations of children to live their lives to the fullest.

Our comprehensive assessment and treatment for children with cerebral palsy, spina bifida and related disorders includes: Neurology, Medical Services, Nursing, Urology, Orthopedics, Physical Therapy, Occupational Therapy, Orthotist, Clinical Psychology, Neuro-Psychology, Seating, Feeding, as well as Rhizotomy, Spasticity and Movement Disorder clinics.

And unlike many programs, we see patients beyond age 18. Call Kennedy Krieger Institute today. We're here to help.

Kennedy Krieger Institute
707 North Broadway • Baltimore, MD 21205
www.kennedykrieger.org

1-888-554-2080
Kennedy Krieger Institute's Toll-Free Referral Line

Circle #47 or visit www.eparent.com/adinfo

715

VERMONT PARENT DOCTOR TEAM DESIGNS A MEDICAL HOME FOR CHILDREN WITH SPECIAL HEALTHCARE NEEDS

by Elizabeth Wehr

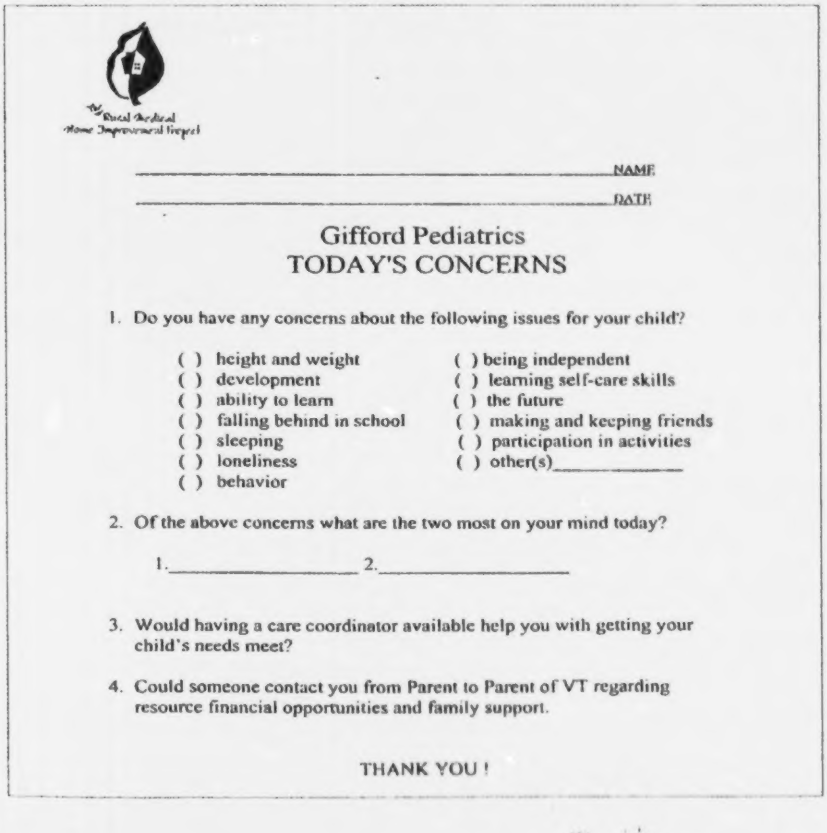
When parents of children with special needs arrive for office visits at Gifford Pediatrics, in Randolph, Vermont, they receive a simple, one-page questionnaire about their immediate concerns. (See below.) Parents can check off any of a dozen possible items, ranging from their child's height and weight to loneliness, falling behind in school and making and keeping friends. Parents can also write in other concerns, and they are specifically asked to indicate which two are "most on their mind today." For parent Kim Daniels the form is a welcome invitation from her son's pediatrician, Dr. Louis DiNicola, to talk with him about "the things that are on my mind—not just medicine and tests."

The questionnaire and other special features of the Randolph, Vermont practice are also meant to help parents obtain other community resources and connect to other families and professionals. For example, the questionnaire asks parents whether having a care coordinator could help in getting their child's needs met. It also asks whether they would like to be contacted about financial resources and family support by the state's Parent to Parent organization. Betsy Hannah, the nurse and care coordinator at the Gifford practice, often helps parents complete the form. If they wish, she sits in while parents discuss their concerns with their children's doctor and then she follows up later.

The questionnaire, the care coordination and an informal parents' network are designed to make the practice a "medical home" for children with special healthcare needs. Some special features are meant to minimize potential problems in office visits. Kim Daniels reports that the entire office staff knows that spending time in the waiting room is too challenging for her son, Troy, although another child "can get through any visit – so long as there's a blue balloon" waiting for him. If necessary, the staff may schedule a senior volunteer to park a family's car.

Other special services of the Gifford practice go well beyond dispensing balloons, valet parking and medical services. Parents call Betsy Hannah for help with school problems, parent contacts and, sometimes, just to talk about feeling overwhelmed by their child's needs. She also can put them in touch with a resource parent, who helps them qualify their children for SSI (Supplemental Security Income), Medicaid, personal care assistance and other forms of aid. Dr. DiNicola meets monthly with interested parents to talk about such topics as ADHD and adolescent transitions. Parents trade equipment and experiences among themselves.

For parents, the practice has evolved into a single point of entry, a term referring to the idea of one identifiable place in a community where parents can learn about and gain access to the bewildering array of health services and therapies, financing options, special equipment, early interventions, special



The Rural Medical Home Improvement Project

______________________________ NAME

______________________________ DATE

Gifford Pediatrics
TODAY'S CONCERNS

1. Do you have any concerns about the following issues for your child?

( ) height and weight
( ) development
( ) ability to learn
( ) falling behind in school
( ) sleeping
( ) loneliness
( ) behavior
( ) being independent
( ) learning self-care skills
( ) the future
( ) making and keeping friends
( ) participation in activities
( ) other(s)____________

2. Of the above concerns what are the two most on your mind today?

1.________________ 2.________________

3. Would having a care coordinator available help you with getting your child's needs meet?

4. Could someone contact you from Parent to Parent of VT regarding resource financial opportunities and family support.

THANK YOU !

education classes and social supports that their children may need as they grow up.

The medical home design team. Ten years ago, the American Academy of Pediatrics (AAP) adopted a "medical home" policy recommending that a child's physician be responsible for all aspects of a child's healthcare, including "interaction with school and community agencies to be certain that special health needs of the individual child are addressed." Working with the AAP and the national parents' organization, Family Voices, the federal Maternal and Child Health Bureau (MCHB), its state offices and grantees are developing materials and testing methods for putting medical home principles into practice.

Dr. Louis DiNicola and Nurse Betsy Hannah with two of their patients, Calub Collins and Jessica Russell.

What is interesting about Gifford Pediatrics is that Dr. DiNicola and his office staff have worked with Kim Daniels and other parents to translate the medical home concept into a reality. The catalyst for this process was the Lebanon, New Hampshire Center for Medical Home Improvement, which receives MCHB and other grant support. Center co-directors Jeanne W. McAllister and Dr. W. Clark Cooley provided start-up technical assistance to Gifford Pediatrics and three other practices in Vermont and New Hampshire. They are now working with thirteen additional practices.

To receive technical assistance from the Center staff, a physician must agree to work together with his office staff and with the parents of children with special needs. Doctors must also commit the time needed to work together with the team. The Center allows each individual practice's team to define their priorities and decide how to address them. According to both the Center and the Gifford practice team, medical home improvements can only alter a medical practice if the team itself dreams and owns the improvements. The role of the Center's staff is to support these processes, by facilitating meetings, providing information and otherwise helping teams realize their goals.

As they work with practice teams, the Center staff also develops and tests methods for identifying children with special needs, survey instruments for physician practices and other "do-it-yourself" materials for physicians and interested parties. The Center characterizes its materials as "tools" that serve to improve the process of care in medical practices by relying heavily on families' insights. In fact, a Medical Home Improvement Kit published electronically by the Center warns that its tools "won't work without engaging parents of children with special needs as partners in the process of...improving care."

Steps in designing a medical home. Like any home, the medical version must be built one step at a time. The first, and most important, step is to determine whether a physician would be comfortable with the team process and with the goals that emerged in the Gifford practice. As Dr. DiNicola says, a physician must have a professional commitment to including highly challenging children in his or her practice. Long before he became involved with the medical home project, Dr. DiNicola was participating in an informal network of northern New England pediatricians who wanted to apply their professional training to children with special needs, instead of routinely referring them to major medical centers.

A physician must also be interested in working with parents as partners, not only in the care of their children but in evaluating and improving his or her practice as well. Everyone involved with the Gifford practice team advises parents and doctors to start with small steps and let ideas emerge over time. For example, as Center researchers were surveying the practice, the practice team began to consider how information about the needs of individual children could be incorporated into day-to-day office routines. One result was the "Today's Concerns" questionnaire. Another was a short script, worked out with the office receptionist, so that she would remember to ask about special needs when a parent called to schedule a child's office visit. Then the team created a two-page "Medical Care Plan" form to supplement a child's medical record. The form provides "at-a-glance" information—everything from a child's medications, devices and specialized services to his or her nickname and unique family needs/assets. When a child's primary care doctor isn't available, the form enables the treating physician to know, for example, that a child cannot tolerate the use of a tongue depressor. The

continued on page 74

continued from page 73

Center's technical assistance was essential for some of the accomplishments of the Gifford practice. For instance, the care coordination that Betsy Hannah provides is now financed by the state's Medicaid program. Data collected and analyzed by Center researchers in collaboration with a managed care organization showed that care coordination saved money because it lowered rates of emergency room and hospital admissions for children with special needs.

Technical assistance also helped the Gifford practice team when it approached local school officials about ensuring that children received the therapies at school that Dr. DiNicola prescribed. At the first meeting, a professional facilitator kept conflicting priorities from stalemating discussions among the parents, healthcare professionals and school officials. Ultimately, all parties collaborated to develop a unified form that includes medical information for schools, school information for the physician and parents' preferences. The form also helps structure periodic meetings where parents, teachers, school officials, Dr. DiNicola, Betsy Hannah and others discuss a child's individual needs. (A modified version of this four-page form appears on pages 75-77; the Comments page has been omitted due to space limitations.

No one finds it easy to change familiar routines that reflect their experiences and education or training. Given their direct responsibilities for the health and wellbeing of patients—and the demands on doctors' time, it may be especially difficult for physicians to contemplate either the process or the results of designing a multipurpose medical home for children with special healthcare needs. But the payoff, according to the team at the Gifford practice, is healthier children and stronger families. "The most important thing," concludes Dr. DiNicola, "is to get the parents involved."

Resources for Exceptional Parents. Two of the forms developed by the Gifford Pediatrics team are reproduced with this article. These could be the basis for beginning discussions among parents; but the team process of developing individualized forms and other strategies is considered important for the success of any new practice.

The Center for Medical Home Improvement, at Children's Hospital at Dartmouth-Hitchcock Medical Center, New Hampshire, publishes its Medical Home Improvement Kit and other materials on its Website, where a video on developing a medical home for children with special healthcare needs may be viewed (http://www.medicalhomeimprovement.org). Various types of

continued on page 78

Standing Small, Growing Tall

Classroom inclusion is now achievable! With the EasyStand, kids can sit when their classmates are sitting and stand when they are standing. The EasyStand line of pediatric & youth standers is perfect for home and school. From early intervention through high school, we can stand all your students.

Call today for more information on how to ***try one free!***

EasyStand Magician•ei
Height Range: 28"-40"

EasyStand 7000 Magician
Height Range: 36"-54"

EasyStand 5000 Youth
Height Range: 4'0"-5'6"

AltimateMedical
262 West First Street Morton, MN 56270

800•342•8968 507•697•6393
www.easystand.com

EASYStand®

Circle #18 or visit www.eparent.com/adinfo

Gifford Pediatrics
A Medical Home* for Children with Special Health Care Needs (CSHCNs)

The purpose of this document is to enable parents/guardians, medical providers and appropriate school personnel to exchange information regarding a child's special health and educational needs and related services. While this document belongs to the child's parent or guardian, one copy will reside with the child's health care provider ____(Name/Practice), and one copy with the child's school__________________________(School Name).

Information Exchange for:____

Female______**Male**_______**Date of Birth**______**Grade**______**School Year**_______

Parents/Guardian:_________________________**Phone Number:**__________
Preferred Method/Time of Contact:
____

Primary Medical Provider:___________________**Phone Number:**__________
Preferred Method/Time of Contact:
____

Medical Care Coordinator: _______________**Phone Number:**__________
Preferred Method/Time of Contact:
____

School Contact(s) :_________________________**Phone Number:**__________
Preferred Method/Time of Contact:___________________________________
____

Other Key/Medical Providers:
_______________________________________**Phone Number:**__________
_______________________________________**Phone Number:**__________

Permission Releases

I ______________________________(parent/guardian) give permission to ___________________________(health care provider) to share *the information on this form* with my child's school__________________________(school name) via the named school primary contact. I give permission for my child's school to share *the information on this form* back to my child's provider____________________________________.

Signature:____Date:__________

When *this information* is discussed via phone, in person, or otherwise I would like:
___It to be documented in my child's chart where I may see it.
___A phone call informing me of said communication (within 24-36 hours).
___Other:____

Document created (date)_________Updated__________Next update due__________

Family/Practice/School
Information Exchange

Medical Information for Schools

To Be Filled Out By Provider and Parents/Guardian

Information Exchange for: ____________________

Health Information and Medical Needs

I. Medical Data

Primary Diagnosis(es): ____________________

Secondary Diagnosis(es): ____________________

Other Specialties Involved: ____________________

____

Medications: ____________________ Medical Therapies/Treatments: ____________________

____________________ / ____________________

____________________ / ____________________

Special Instructions (and/or staff training):

____

____

This child's condition, illness symptoms, and/or medications/treatments may affect the following:

- ☐ Attendance
- ☐ Memory
- ☐ Attention
- ☐ Learning
- ☐ Fire drills
- ☐ Vision
- ☐ Hearing
- ☐ Triggers
- ☐ Thirst/Appetite
- ☐ Mobility/motor skills
- ☐ Peer Interactions
- ☐ Personality
- ☐ Toileting/Hygiene
- ☐ Continuity/Stability
- ☐ Participation
- ☐ Other ____________
- ☐ Stamina/Fatigue
- ☐ Meals/ Foods/Feeding
- ☐ Transportation
- ☐ Academic testing
- ☐ Physical education
- ☐ Field Trips/ Events
- ☐ Playground/Recess
- ☐ Other ____________
- ☐ Oral expression
- ☐ Articulation
- ☐ Written expression
- ☐ Listening comprehension
- ☐ Reading comprehension
- ☐ Math reasoning
- ☐ Sensori-motor integration
- ☐ Other ____________

If a box is checked, please comment explicitly below:

____

____

____

____

____

____

____

Needs and Goals

The Individual Child/Family: Assets &Needs, Goals &Actions

____

____

____

____

____

____

____

Parent/Guardian Signature: ____________________ Date: ____________

Provider Signature: ____________________ Date: ____________ Next update: ______

School Information for Provider

To Be Completed by School Representative and Parent/Guardian

Information Exchange for:____

School Services and Therapies

I. The Child At School

Individualized Education Program (IEP): ☐ YES ☐ NO

Created (date):_________ Last Review (date):______/______ Next Review (date):______/______/

Other Accommodations: ☐ YES ☐ NO

Describe:____

____

Related Services	✓	From an assistant?	Goals being met? Yes/No	Comments:
Occupational Therapy (OT)		Yes/No	Yes/No	
Physical Therapy (PT)		Yes/No	Yes/No	
Speech/Language		Yes/No	Yes/No	
Assistive Technology		Yes/No	Yes/No	
Other:		Yes/No	Yes/No	

Please comment on other related services (e.g. accommodations, assistive technology, school health/social/or counseling services, adaptive PE, etc). See the note section on back.

____

____

Concerns: This child's condition, illness symptoms, and/or medications/treatments may affect the following:

- ☐ Attendance
- ☐ Memory
- ☐ Attention
- ☐ Learning
- ☐ Fire drills
- ☐ Vision
- ☐ Hearing
- ☐ Triggers
- ☐ Thirst/Appetite
- ☐ Mobility/motor skills
- ☐ Peer Interactions
- ☐ Personality
- ☐ Toileting/Hygiene
- ☐ Continuity/Stability
- ☐ Participation
- ☐ Other______________
- ☐ Stamina/Fatigue
- ☐ Meals/ Foods/Feeding
- ☐ Transportation
- ☐ Academic testing
- ☐ Physical education
- ☐ Field Trips/ Events
- ☐ Playground/Recess
- ☐ Other______________
- ☐ Oral expression
- ☐ Articulation
- ☐ Written expression
- ☐ Listening comprehension
- ☐ Reading comprehension
- ☐ Math reasoning
- ☐ Sensori-motor integration
- ☐ Other______________

If a box is checked, please comment explicitly below:

____

____

Needs and Goals

Summary of School Goals, IEP, or Other Services:

____

____

____

____

Parent/Guardian Signature:______________________________ Date:__________

School Contact Signature:______________________________ Date:__________ Next update:__________

THE **Adjustable® Bath Chair**
by DURALIFE

30L-B
30M-B

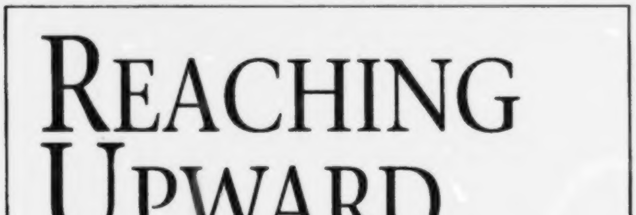
- 9" leg extensions available.
- Adjusts to multiple positions for individualized comfort.
- Safe, quick push-button adjustment mechanism located out of child's reach.
- Highly durable, comfortable mesh fabric is easy to clean and dries fast.
- Safety straps included for those who require extra support.

TWO great styles to choose from!

Model 20
Model 350
Pediatric Shower/ Commode Chair

DURALIFE, INC.
Call Toll Free: 1-800-443-5433
Fax: 570-323-9762
E-mail: duralfe@aol.com
Website: www.duralife-usa.com

Circle #33 or visit www.eparent.com/adinfo



REACHING UPWARD

AT THE EVERGREEN CENTER, we believe in learning as a means to personal independence. Combining school and community residence programs, The Evergreen Center creates an individual education program that helps each student become a part of the community.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631
Serving students with developmental, medical and behavioral needs since 1981.

Circle #37 or visit www.eparent.com/adinfo

Kim Daniels and her son, Troy.

continued from page 74

resources, training materials and notices of medical home grant initiatives are available at the home page of the National Center of Medical Home Initiatives for Children with Special Health Care Needs (http://www.medicalhome-info.org), which is a joint project of the American Academy of Pediatrics, Family Voices, Shriners Hospitals for Children and the National Association of Children's Hospitals and Related Institutions. Assistance for and information about medical home projects in each state is also available from directors of children with special healthcare needs programs at MCHB-supported state agencies. To locate these agencies, go to http://www.mchb.hrsa.gov/programs/block-grant/directors.htm. EP

NOTE: This article describes one of more than two dozen programs and promising strategies for providing community-based health services. These programs were described in a report prepared by Dr. Kathleen Braden of the Eunice K. Shriver Center in Waltham, Massachusetts, for the 2001 Surgeon General's Conference on Health Disparities and Mental Retardation. Summary descriptions of and contact information for all of the programs in Dr. Braden's report, were published in the February 2002 report of the conference, Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation (www.surgeongeneral.gov). Additional model programs will be featured in upcoming issues of EP.

Elizabeth Wehr is a consultant and a former Senior Research Scientist at the Center for Health Services Research and Policy at George Washington University, specializing in issues involving children with special health needs and access to care

www.abilitiesexpo.com

EXPO

Greater Cleveland
I-X Center
July 19-21

Chicago Metro
Donald E. Stephens
Convention Center
August 16-18

New England
Bayside Expo Center
September 20-22

Northern California
San Mateo County
Expo Center
November 22-24

Education and *Equipment* to *Empower.*

Come **sample products** and **talk one-on-one** with service providers. As our guest you can attend **complimentary educational workshops** on everything from better sex to better jobs. Or perhaps you would like to see the power of new technologies in our **Access Ability Pavilion.** There are many options for you at **Abilities Expo.**

For more information please call (800) 385-3085 or (218) 723-9130 outside of the USA.
www.abilitiesexpo.com

abilities
EXPO

PRESENT THIS COUPON FOR FREE ADMISSION

[ADMIT ONE]

Bring coupon to any **2002 Abilities Expo** and save the $5 on-site registration fee.
Coupon must be filled out to be valid and may be photocopied for additional registrants.

NAME: ____________________

ADDRESS: ____________________

CITY: ____________ STATE: ______ ZIP: ____________

For information call:
(800) 385-3085
(218) 723-9130 (outside USA)

Produced and Managed by:

ADVANSTAR
COMMUNICATIONS

♿ All events are wheelchair accessible

© 2002 Advanstar Communications Inc. All rights reserved.

Circle #17 or visit www.eparent.com/adinfo

"Snapshots of Your Life"

by Lori Pedersen

A blue-eyed miracle to behold...
Running across the yard, blond hair blowing in the wind, so happy, so energetic...
Loving and living each moment in time,
Making it all your own.

Sleepily waving your love to me as the tears fall silently down my cheeks and onto the floor...
The door closing to the operating suite as they prepare you for open-heart surgery...
Trusting God for your life.

A new exciting door opens for you...the first day of kindergarten.
Yet, as the year passes, the door closes on hopes... you "just have a speech problem"...
We learn new meanings to the words "mental retardation," "chromosome abnormality,"
"special education"...
"Institutionalize the child."

Fall drifts along year after year and with each new year, your joy of school and learning grows by leaps and bounds. Defiantly struggling to disprove the predictions...
You grasp each new concept and never let it go.

Rachel ready for the Prom

Rachel wearing her Prom Princess crown.

Special Olympics...the time of year you anticipate so greatly, that it constantly fills your thoughts and words. The time of year that you don't have to be afraid of others. The time of year that you can be Rachel and live Rachel and love Rachel for every single thing that makes her unique and priceless.
Your moment in the sun...pure, unblemished joy...too much to contain...

Sunday morning...it's time to go to church...you put on your prettiest dresses and we place ribbons in your hair...
You sing and clap your hands to the wonderful, loving God,
Who has so obviously held you in His arms and carried you throughout your life,
Blessing you, and all of those you touch with your joy of living.
"She'll never read." And yet I sit amazed as you read the fifth-grade book to me...
You read the signs as we drive down the road...the recipe books...letters from our family...
You are reading.

EP selects "parent editorials" for the purpose of providing a forum for emerging opinions and evolving parenting philosophies. EP also welcomes responses to previous editorials that represent divergent views. These select editorials do not necessarily reflect the opinion of EP. — Rick Rader, MD, Editor-in-Chief

The same operating suite...and more tears..."Spinal Fusion...Scoliosis is crippling her...Possibility of a wheelchair if we don't proceed"...Several hours, Pediatric ICU, Orthopedic floor, upper body brace...You come home...you can't get up without your brace...

I roll you, brace you, powder you, dress you, bathe you; from June through October...

The brace is removed and you now have the figure of a woman.

Where did that come from?

Hello Junior High...Goodbye Miss Meyer...how we do love you...junior high, a success...You love school.

You're a student council rep for your grades...you take Home Ec...more Special Olympics...Chorus with Mr. Jackson... concerts...the big trip to Jefferson City with the student council and Grandpa gets to go with you on the 'luxury bus'...Christian Alliance...lock-ins...dances...

"Mom, a boy SLOW-DANCED with me"...Eighth-grade Graduation.

Rachel walking in at high school graduation

Grandma Nana, Emily, me, and you...shopping for two hours to find you the right dress...Grandpa dropping off your corsage...ordering your graduation cake...getting seats four rows from the front row...hearing the music and seeing you walk to your seat, with your classmates; so proud of the difficult, nearly impossible road that you've walked to earn that diploma...tears fighting their way down my cheeks as I recall each of these snapshots and see you know...I am so incredibly proud of you and want to tell everyone, THIS is MY beautiful daughter...and to tell the people, who are so quick to hand out the label, "mentally retarded", cloaked with its chains and bondage and shame...that they could give it wings of hope...for they are just two words...two...words. Words that should not hide the beauty of the soul of those that they speak of, but two words that should shine an illuminating light on the pathway of experiencing just such a relationship with these that God created and loves. **EP**

Lori Pedersen of Pevely, MO, wrote this poem for her daughter, Rachel, on the occasion of her junior high school graduation in May 1997. Rachel endured a number of disabilities, including mental retardation, attention deficit/ hyperactivity disorder, a heart defect, scoliosis and a number of other extensive problems requiring multiple surgeries. The final stanza was added when Rachel graduated high school last June. The accompanying pictures show Rachel at her high school graduation and as the first-ever Herculaneum High School Prom Princess elected by her senior class. She received a "School Spirit" award her senior year, in part for her work as basketball manager for the boys and girls varsity basketball teams. Sadly, Rachel passed away suddenly on November 11, 2001. Though Pevely is a small town, more than 1,000 people turned out for her visitation and funeral. At her class's request, Herculaneum High has established an award plaque that bears her name; each year, a student will be honored as receiving the Rachel Pedersen School Spirit Award.

Lori Pedersen works as a Site Supervisor for a day rehabilitation support service program for adults with developmental disabilities at Developmental Services of Jefferson County, MO.

Parents may send their submissions for Parent Perspective to Exceptional Parent Magazine, 65 E. Route 4, River Edge, NJ 07661; e-mail: epedit@aol.com
All submissions are subject to review and editing by EP.

SPORT CORNER
NDSA

ON TRACK WITH TRACK AND FIELD SPORTS

by Carol Keller, PT

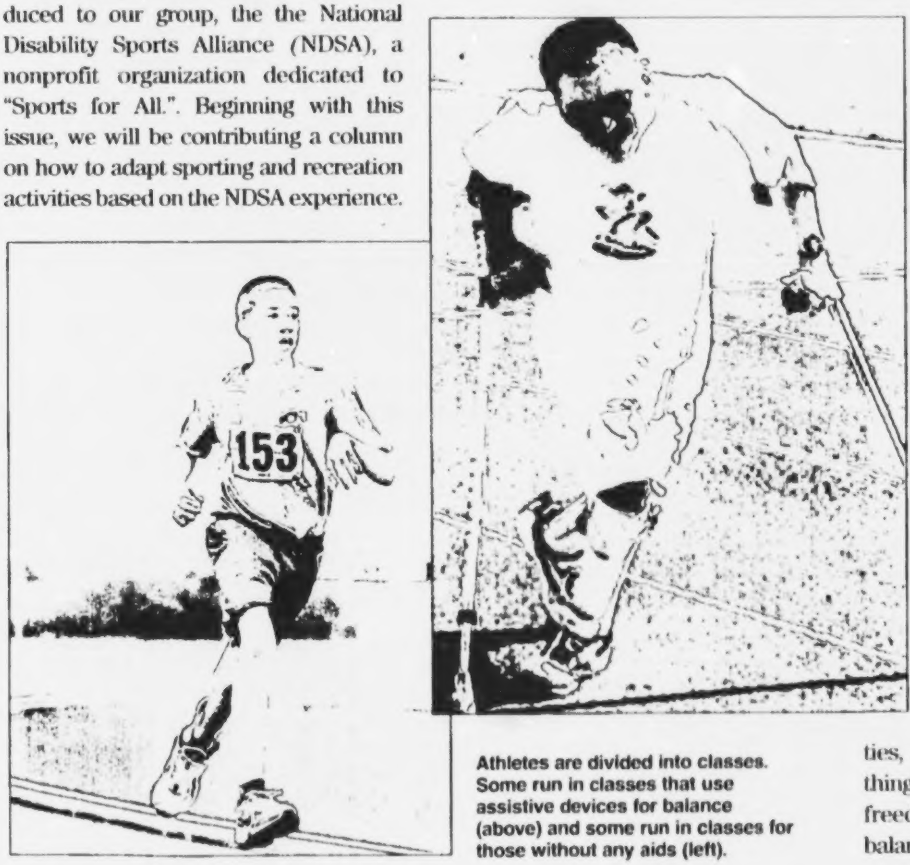
EP is proud to *PRESENT THE FIRST OF NDSA'S ONGOING COLUMN DISCUSSING INCLUSIVE AND COMPETITIVE SPORTS AS WELL AS RECREATION ACTIVITIES. —THE EDITORS*

Last month, EP's readers were introduced to our group, the the National Disability Sports Alliance (NDSA), a nonprofit organization dedicated to "Sports for All.". Beginning with this issue, we will be contributing a column on how to adapt sporting and recreation activities based on the NDSA experience.

We thought it would be appropriate to start this series by describing a sport that is relatively simple to coordinate for parents and others who wish to begin their own adaptive sports program: track and field activities. With these activities, it doesn't matter if you only have a few participants—one athlete can even practice alone, although it is not as much fun as having teammates. Another advantage is that the events don't have many complicated rules to learn.

Some NDSA track and field events are the same as those typically associated with the sport, such as the 100, 200 and 400 meter races and do not require any modification. But there are also specialized events. For the younger athletes in the junior division, the distances offered include 20 and 60 meters. There is a "weave" event for power chair users which requires the athlete to move down the track, zigzagging between cones. All wheelchair classes may compete in the slalom. (See picture.) The slalom is an obstacle course requiring attention to the course and control of the wheelchair's movement.

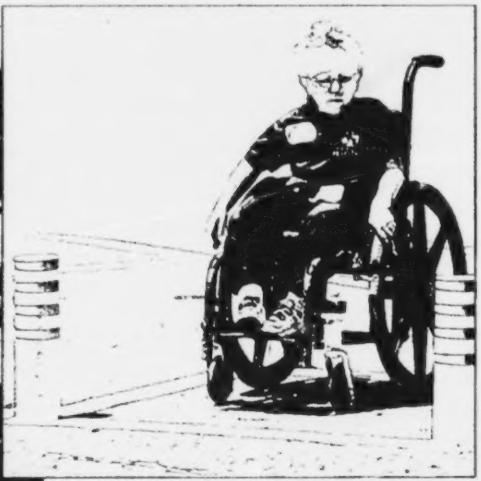
In all track events, athletes compete against others who have been placed in the same classification group. NDSA athlete's are assigned a classification group based on his or her functional abilities to assure equitable competition. We use four classifications for wheelchair users, including power chairs, and four classifications for individuals who can walk. A brief description of the classification system follows which can give a general idea of where an individual may fit in the system. (It is important to note that a "classification team" should do an assessment to determine every athlete's true classification. A classification team typically consists of two or three individuals such as physical therapists, physicians, and sports/recreation professionals. Classifiers have been trained and certified by NDSA to test and observe an athlete's movement patterns, abilities, and limitations. They look at such things as how the athlete grasps objects, freedom of movement in limbs, and balance.



Athletes are divided into classes. Some run in classes that use assistive devices for balance (above) and some run in classes for those without any aids (left).

CLASS 1 Severe involvement in all four limbs. Limited trunk control. Unable to grasp a softball. Unable to propel a wheelchair.

CLASS 2 Severe to moderate involvement of all limbs. Propels wheelchair very slowly or pushes with feet. Poor functional strength and severe control problems in arms.



High Toss (Top and Bottom photos): Athletes competing in the high toss must toss a wooden club (or soft shot put) over a high jump standard.

Slalom (Middle photo): Part of the slalom course requires an athlete to complete a 180 degree turn within the boundaries of the "reverse gate." Penalties are given for crossing over the lines or knocking cones over.

CLASS 3 Moderate involvement of all limbs with fair functional strength and minimal control problems in arms and torso. Uses wheelchair.

CLASS 4 Legs have moderate to severe involvement. Good strength and minimal control problems in arms and torso. Uses wheelchair.

CLASS 5 Legs have moderate to severe involvement. Good strength and minimal control problems in arms and torso. Uses wheelchair.

CLASS 6 Walks with moderate to severe involvement of all limbs. Does not use assistive devices for balance. Balance problems when running or throwing. More arm involvement than Class 5.

CLASS 7 Moderate to minimal involvement on one side. Good functional ability on non affected side. Walks/runs with noted limp.

CLASS 8 Minimally affected. May have minimal coordination problems. Runs and jumps freely. Has good balance.

The field events have many modifications. Familiar events, such as the shot put, discus and javelin, are offered for some classifications with the weight of the implement varying with the classification. Examples of some modified events include: throwing a wooden club, tossing a soft shot (a small leather bag filled with shots) over a high jump standard, tossing the soft shot for precision at a target and kicking a rubber ball for distance.

If this has grabbed your attention and you want more information about specific track and field events, NDSA rulebooks are available and recommended. You can also inquire about competitions or programs in your area. Contact the National Disability Sports Alliance at: 25 West Independence Way, Kingston, RI 02881; phone: (401) 792-7130; Web site: http://www.ndsaonline.org. ■

Carol Keller, PT is the NDSA Sports Manager for Youth Sports. She lives in Derby, KS, where she works as a school system physical therapist. Carol is the volunteer coach for the Free Spirits, a track team for athletes with disabilities. She has organized an annual regional track meet for physically challenged athletes, the Challenge Games, since 1989.

Traumatic Brain Injury, Then and Now

by Jan Blacher, PhD

Jack and Jill went up the hill...Jack fell down and broke his crown
Humpty-Dumpty sat on a wall, Humpty Dumpty had a great fall...
Rock-a-bye baby on the treetop...when the bough breaks
the cradle will fall...

Summertime, and the livin' is ... dangerous. Most children are home from school, and many zip along sidewalks and streets on bicycles, skateboards and in-line skates. So, too, do newly licensed teenagers and, presumably, seasoned drivers cruise the roadways. Accidents happen. And the result is often more than a sprained wrist or ankle.

The National Pediatric Trauma Registry in the United States tracks data on the more than 80,000 children who sustain trauma each year. According to Ronald Savage, an expert in traumatic brain injury (TBI), just as many children recorded in this databank sustained traumatic brain injury as fractures.

How many children suffer head trauma? A lot! Published estimates place the incidence of significant head trauma between 200 and 300 per 100,000 children and adolescents, or between 54,000 and 81,000 per year in the US. That number is probably even higher since symptoms of brain injury are similar to other categories in special education that are more familiar to school personnel. Many children with TBI are incorrectly classified by registries or databanks in special education as being learning disabled, developmentally disabled, emotionally disturbed or as having attention deficit hyperactivity disorder.

The term "traumatic brain injury" refers to a specific type of disability that occurs after birth (usually, but not always, due to accident or abuse); in fact, it is sometimes referred to as "acquired brain injury," as opposed to something with a genetic or "unknown" cause.

The consequences of TBI depend heavily on the type of injury, on the part of the brain where the injury occurred and on the age of the child. At one time it was assumed that children would recover better and more quickly if the accident occurred in early childhood, in the belief that brain plasticity would aid in recovery. Now it is recognized that younger children, ages birth to five years, have a more difficult time recovering because their brains are injured during a period of rapid brain growth and maturation. Indeed, since older adolescents and young adults have simply had a longer time living and coping with daily events, they have more practical knowledge and experience to help compensate for an injury to the brain. This new knowledge makes the fact that the majority of brain injuries occur in children under the age of 10 even more cause for concern. Incidentally, twice as many boys as

continued on page 86

Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, where she has been a researcher for more than 25 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of retardation, dual diagnosis and the transition to adulthood. Dr. Blacher has developed **Research Reflections** as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to **Research Reflections** and any suggestions you might have. Send e-mail to: jan.blacher@ucr.edu.

Information and support for the special needs community

PARENTS ○ FAMILIES ○ PHYSICIANS ○ PROFESSIONALS

Exceptional Parent Magazine

Welcome Resources Technology Edu/Toys Healthcare Subscribe

eparent.com

New! Visit the EP Web site, EParent.com, and discover...

TOYS—The new eToys Web site (www.etoys.com) teams with EP's Web site, EParent.com (www.eparent.com) to offer ideas, information and imaginative toys for families with kids who have special needs. When parents, teachers or caregivers shop at eToys and visit the co-branded EParent.com site, they'll find hand picked toys and games, plus featured articles from EP Magazine. The site also features direct links to the EParent.com shop at eToys, and eToys products recommended by experts or reviewed by organizations chosen by EP Magazine.

EDUCATION—EParent.com's newly-constructed Education channel (EDU/TOYS tab) yields a wealth of current articles on topics such as IDEA, IEPs, assistive technology, transitioning and inclusion. These are supplemented by a growing directory of schools, camps & residences, which can be found in the "Directories" link of the "Resources" channel.

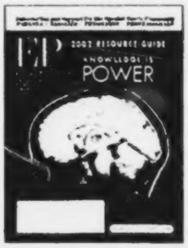
ON-LINE ARCHIVES—Now, EParent.com users can preform keyword searches through our on-line archives and purchase articles which have appeared, as far back as in the eighties, in EP Magazine (recipient of awards from Folio:The Magazine for Magazine Management, Easter Seals, Consumer Healthcare Group). These include classic pieces on such subjects as early childhood, rare disorders, technology, education, medical research update, transitioning, travel, all of which have distinguished EP Magazine through the years.

MORE TO COME IN 2002—You can also click through our EP Library (www.eplibrary.com) which contains books, videos and software encompassing almost 50 specific and general categories, with more than 650 titles. Of course, we will continue to refresh and improve EParent.com in 2002, and look forward to receiving your comments and suggestions. Log on and find out what we are all about!

EP Exceptional Parent

Click here for our Text only site.

NOW SUBSCRIBE ON-LINE



National Resource Directory

www.eparent.com

WWW.EPLIBRARY.COM
EP LIBRARY
THE SPECIAL NEEDS BOOKSTORE

continued from page 84

girls sustain a traumatic brain injury.

What are some of the common causes of TBI? The national registry on brain injury, mentioned above, reports that most pediatric TBI injuries result from motor vehicle collisions (27.1%) and falls (26.5%), like the one Jack, and so many others in classic nursery rhymes, took. Yet the number of brain injuries resulting from bicycle accidents (9.7%) or sports (5%) is also daunting. In an infant TBI is usually due to either child abuse or a fall.

Do certain activities place a child at risk? Despite their propensity to recover skills more quickly, older children and youth are more likely to engage in sports, a widespread risk factor for head injury. In the old days, coaches and even parents were quick to dismiss head injuries as "bell ringers" or just as part of the game. Today we are well aware that playing sports can carry a risk of concussion, a mild form of brain injury. Football is not solely to blame, although it is certainly the main culprit. High risk is also associated with ice hockey, rugby, martial arts, soccer and horseback riding.

James Kelly and Ronald Savage have written eloquently about how best to evaluate concussions in sports, whether—or when—the athlete should re-enter the sport, and what parents and educators should be aware of when the athlete returns to play. Their report draws on data from the Centers for Disease Control and Prevention estimating 300,000 sports-related concussions in the US each year.

Kelly and Savage provide explicit guidelines for determining whether to return an athlete, or a child, to the game. For example, according to their guidelines, after a grade 1 or mild concussion, an athlete can be returned to play only if he or she is symptom-free at rest, or symptom-free with exertion within 15 minutes of the injury. In a grade 2 or moderate concussion, the individual should refrain from sports for at least a week. In a grade 3 concussion, which is the most severe, there is typically a loss of consciousness; thus, return to play should occur after a minimum one-month recovery. However, there are exceptions and caveats even to these guidelines, allowing more or less rest and recommendations for follow-up examination.

In an extensive review of neuropsychology's contribution to understanding brain injury during sports, Ruben Echemendia and Laura Julian propose that neuropsychological tests may be more useful than traditional neuroimaging techniques because they can detect subtle losses in an athlete's attention and concentration. Echemendia and Julian also note that these traditional neuroimaging techniques, such as computerized tomography (CT) and magnetic resonance imaging (MRI), may not detect abnormalities, even when the injured child or his parents report somatic complaints or cognitive impairment following the concussion.

Most parents (and educators and

The Many Faces of Matheny.

A lifetime of caring for people with developmental disabilities.

Award-winning programs for children and adults in medicine, dentistry, therapy, and education

- Residential
- Outpatient
- Respite

As an affiliate of major universities and hospitals, Matheny shares its expertise with the medical community.

MATHENY
School and Hospital
Main Street, P.O. Box 339
Peapack, NJ 07977
908.234.0011
www.matheny.org

Circle 651 or visit www.eparent.com/adinfo

coaches for that matter) are not aware of post-concussion syndrome, which refers to repeated concussions over an extended period of time. Obviously, the more frequent the concussions, the greater the likelihood that there will be neurological, cognitive and/or behavioral deficits in the child or young adult.

It is important that parents, teachers and other professionals who work with the child monitor his or her cognitive, behavioral and physical changes for six to eight weeks following an injury. Fortunately, with a first injury, no permanent negative effect is likely, and full recovery of the injured child is expected. But, because a child active in sports can have four or more different coaches during high school, parents must be responsible for being aware of their child's injury history and making sure each new coach is also kept apprised.

Does a child's "special need" immunize him at all from further traumatic brain injury? Sadly, no. In fact, some children with special needs are at even higher risk for injury than children in the general population. For example, children whose behavior is characterized by inattention, impulsivity, hyperactivity, highly disturbed reactions, aggression, irritability and/or depression are less likely to be tuned into what is going on around them. They are more likely to engage in risky or careless behaviors—such as stepping in front of a moving vehicle—which can lead to injury.

Researcher Jenny Sherrard and her colleagues in Australia recently published results of a large-scale study on injury risk in about 500 young people ages 4 to 18 years with an intellectual disability. The investigators used data collected across two time periods five years apart, which allowed them to calculate risk factors over time. Parents answered questionnaires about the child's development and behavior and about family functioning and economic status. The authors identified three risk factors highly associated with injury:

continued on page 88

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

Coming Soon!

HYPERBARIC OXYGENATION FOR THE COMATOSE CHILD

There is some hope for the comatose child suffering from severe brain injuries, cerebral palsy, or anoxic encephalopathy. Children with Glasgow Coma scales from 3-5 present tremendous financial and emotional burdens, since these little ones may live for many years. When considering care of tracheotomy, gastric tube for feeding, physical therapy, occupational therapy, speech therapy, nursing care, recurrent hospitalizations, medications, vans, and modifications to the home, expenditures may represent multi-million dollars.

Intensive hyperbaric oxygenation is no miracle, but it provides some hope. In certain instances the child is able to communicate verbally, by computer or word board. Eighty percent have the G-tube removed and seventy percent have the tracheotomies closed. Frequently, bowels become normal and nutrition is re-established. Routine monthly medications are reduced and hospitalizations are markedly decreased. Although few children will return fully to society, substantial improvements will give them a better quality of life in addition to a ninety percent reduction in overall costs.

For more information on hyperbaric oxygenation therapy and life planning, call the Ocean Hyperbaric Neurologic Center at (800) 552-0255.

Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child..

by R. A. Neubauer, M.D.

Dr. Neubauer's new book is a complete guide written for the professional as well as the caregiver of exceptional children. The book describes the latest information on hyperbaric oxygenation therapy including improved brain function as visualized through functional imaging. Clinical and scientific data along with references are included.

Call 1-800-552-0255 to order.

(800) 552-0255
• Call for free video & information

For more information, visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #54 or visit www.eparent.com/adinfo

continued from page 87

having epilepsy, which increases the likelihood of falls; having clinically significant levels of behavioral or emotional problems; and having an overly sociable temperament (e.g., attempting more risky activities without a full understanding of the consequences). Clearly, acquiring a brain injury in addition to another disability constitutes a double-whammy for both the child affected and his parents.

How is the family affected by a traumatic brain injury? The caretaking environment provided by parents, the extent of family involvement in rehabilitation, overall family functioning and the appropriateness of a child's educational program upon re-entry to school are all paramount in determining the long-range impact of TBI. Several recent studies by a team of researchers at Case Western Reserve University and Ohio State University (led by H. Gerry Taylor, Keith O. Yeates and colleagues) report on both short- and long-term outcomes for children with TBI. In all cases, children who have moderate or severe TBI and were from socially advantaged homes (whereby parents have higher incomes, more resources and, potentially, fewer family stressors related to the parents' health or work) had lower risk of depression and lower rates of other new psychiatric disorders following injury. These studies determined that "environmental advantages" are critical for predicting positive outcomes in children after injury.

Furthermore, siblings seem to adjust well to having a brother or sister with a serious TBI, as reported in a study by Mary McMahon and her colleagues. These researchers hypothesized that siblings of affected children might have more

Loneliness shouldn't be a side effect of your child's disability.

At Cotting School, boys and girls of all ages and abilities receive countless opportunities to make friends . . . in the classroom, on a field trip, during basketball practice or in physical therapy. As self-esteem increases with each new friendship, talent and personality shine.

OPENINGS FOR YOUNG PEOPLE FOR 2002 – 2003
NEW POSTGRADUATE RESIDENTIAL PROGRAM NOW OPEN

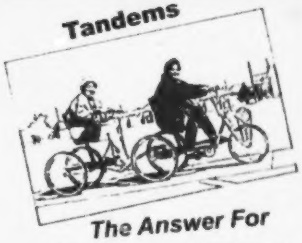
Cotting School — where your child belongs.

For information or a tour, please call Janine Brown-Smith at (781) 862-7323.
www.cotting.org www.cottinghopehouse.org

Cotting SCHOOL

Cotting School is a 766-approved day school in Lexington, MA for children and youth ages 3-22 with physical, communication, and other challenges to learning.

Circle #28 or visit www.eparent.com/adinfo



Custom Fitted Cycles - All Needs - All Ages

Afterburner
Wheelchair Pusher
Tandems
Hand Cycles

The Answer For
- The Blind • Low Muscle Tone
- Motor Skill Training • Mentally Delayed
- Autism • Cerebral Palsy
- Spina Bifida
- Cardiovascular Exercise • *Fun*

THE PERFECT OUTDOOR THERAPY

OutDoor Fun!!!
see us at www.rocknrollcycles.com

Also you can *EARN-A-BIKE*
call 1-800-654-9664
email: funmachines@rocknrollcycles.com

Circle #58 or visit www.eparent.com/adinfo

"acting out" or behavior problems, as well as more "acting in" problems, such as depression or poor self-concept. However, their studies found that there were no significant differences in these areas when, 3 to 18 months after the original injury, the siblings were compared to their classmates. With only 12 siblings involved, this was a small, but clinically useful study. Is this really good news? You bet—because parents can be in control of providing a positive and supportive family environment for both the child with the TBI and any siblings.

Is it possible to pick up all the pieces after a traumatic brain injury? It is heartening to know that rapidly developing technology can better detect brain abnormalities and pinpoint areas of functioning—such as social skills, the management of emotions, mathematical processing and reading—that might be negatively affected. At a more practical level, rehabilitation and education efforts have also advanced, and there is growing awareness of TBI among public school personnel. Promising interventions used successfully with children with learning or cognitive disabilities also seem to work with TBI. For example, "self-monitoring" techniques taught to children with TBI have proven effective for increasing on-task behavior, task accuracy and even improving social skills. If Humpty Dumpty had lived today, it is likely that the neurosurgeons, psychologists, rehabilitation specialists and special education teachers would be pretty successful in putting him back together again. EP

A list of studies referred to in this Research Reflections may be obtained by e-mailing requests to: epedit@aol.com.

Are you home schooling your child with disabilities?

EP Magazine would like to hear from you!

Why did you make this decision?

What kind of program have you developed?

How is it working for you and your child?

Please contact us by fax at 201-489-0633

by e-mail at epedit@aol.com or mail to

EP Magazine
65 East Route 4
River Edge, NJ 07661

Please respond by July 15, 2002

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at **DISCOUNT PRICES!**

As a service to our customers, we offer **FREE SAMPLES** of disposable youth briefs and pull ups.

Save up to 50%

Call **1 800 777 1111** 24Hrs

WOODBURY PRODUCTS, INC.

Order online at: **www.woodburyproducts.com**

Circle #71 or visit www.eparent.com/adinfo

organizational spotlight

The Muscular Dystrophy Family Foundation, Inc.

by Judith R. Duncan

When Frances and Dennis Clouser's son, Luke, was 5 years old, he began having difficulty standing and walking. Eventually, he was diagnosed with Duchenne muscular dystrophy (DMD), a progressive neuromuscular disease affecting primarily males and which limits the lifespan to the teens or early 20s. The Clousers contacted the Muscular Dystrophy Foundation for assistance. Now more than 15 years later, Luke and his family are still clients of the Foundation and strong supporters of the national nonprofit agency.

The Clousers are just one of the multitude of families nationwide served by the Foundation since it was established in 1958. The Foundation's original mission was to provide support services to families in Indiana affected by DMD. In 1997, the Foundation changed its name to the "Muscular Dystrophy Family Foundation®" (MDFF). By adding the word "Family" to its name, the Foundation sought better to reflect its broader mission—to serve the entire family unit. The Foundation understands that a neuromuscular disease doesn't just affect the person with the disease; every member of the family is affected in some way and therefore every member is eligible to receive services.

Luke Clouser

MDFF assists families from the day of diagnosis until their services are no longer required. The Foundation provides items other agencies do not and many items not covered by insurance, including manual and power wheelchairs, hospital beds, van lifts, breathing machines, ramps, shower chairs and computers. MDFF also offers camping scholarships, clinic services, home visits and school and work advocacy as well as assistance with funeral expenses.

In 1997 the Foundation established a toll free number for families to use. As the Foundation soon discovered, limitations imposed by private insurers, Medicare, Medicaid and reduced funding from other sources necessitated the expansion of the Foundation's services to a national level. From 1997 to 2001 the number of requests the Foundation received increased 400 percent.

MDFF increased its staff to handle the increase and began to focus on providing adaptive equipment. Today, MDFF serves families in 49 states and provides services to 43 different neuromuscular diseasesMonthly clinics held at the MDFF office in Indianapolis, Indiana, are open to any child or adult with a neuromuscular disease. As MDFF Vice President Denise Hancock states, "We call our clinic services 'One Stop Shopping' since all the proper disciplines are in place to provide the personalized care our families require." At these clinics, services are available from a wide range of professionals, including a nurse, occupational therapist, physical therapist, genetic counselor and pulmonary specialist. Also on hand to help out are the MDFF medical director and director of social services.

MUSCULAR DYSTROPHY
FAMILY FOUNDATION®
No Boundaries®

Thanks to a recent grant of $40,000 by the Efroymson Fund, a fund of the Central Indiana Community Foundation, the MDFF has been able to add an assistive technology specialist to their cadre of professionals. The specialist facilitates a monthly equipment clinic; orders, maintains and repairs equipment for families; writes letters of medical necessity; and assists clients with insurance claims and Medicaid waivers. The grant will also aid the agency in responding and serving client equipment needs much faster than in the past.

"Families can reach a staff member seven days a week, twenty-four hours a day. Since equipment breaks down after hours and families need emotional support holidays and weekends, we try to be available to our families at all times," Hancock adds.

MDFF has no plans to open offices in other states. The Foundation wants to use its funds to provide services, not for salaries and overhead. MDFF has found that it is more economical for them to fly a staff member to assist a family in another state than to open another office. The Foundation does not charge any fees to families requesting assistance; however, all available family resources must be utilized before MDFF can provide assistance.

MDFF conducts no research and is not affiliated in any way with the MDA or the Jerry Lewis Labor Day telethon. While the MDFF believes that research is extremely important, the organization believes that having the proper equipment and support in order to live an independent and productive life is equally important. The agency's slogan" No Boundaries®" is supported by its mission to offer equipment and support to eliminate boundaries for anyone with a disability.

The Muscular Dystrophy Family Foundation" also focuses on an individual's ability rather than his disability. When Luke Clouser graduated from high school and wanted to attend college, he encountered resistance from many funding sources. These organizations wondered if Luke would be able to keep up with his classes since he required a ventilator to breathe and the full services of a full-time aid. Through the advocacy efforts of MDFF, Luke is now within two classes of obtaining his degree. "We truly don't know how we would have managed if it hadn't been for the Muscular Dystrophy Family Foundation®", says Dennis Clouser. "Whether we need a van lift or a shoulder to lean on–they're always there to help us." EP

For more information, contact:
Muscular Dystrophy Family Foundation®
2330 N. Meridian St.
Indianapolis, IN 46208-5730
Phone: (800) 544-1213 or (317) 923-6333
E-mail: mdff@mdff.org; Web site: http://www.mdff.org

Judith R. Duncan is the President/CEO of MDFF. She is a strong advocate for individuals with disabilities. As a bereavement facilitator, she also conducts workshops nationwide.

Annual Fall Fishing Bash (Bass)

Benefiting the Muscular Dystrophy Family Foundation"

September 14-15, 2002

Dale Hollow ReservoirHorse Creek Marina –

1150 Horse Creek Road, Celina, TN 38551

Cabins and camping available; $150 per team

For more information:(317) 788-9167; (800) 545-2595

For Family Freedom
Get a Superarm Lift

Handicaps, Inc.

- Quick installation
- Doesn't Block Door
- 3 Year waranty
  5 year limited
- Less Cost
- V.A. tested
- Load in seconds
- Less Parking Space

"We are absolutely delighted with the Superarm Lift. The major advantage is the ease and unobtrusiveness with which it mounts to the van. It is so much more attractive than the various elevator contraptions. The lift has increased our son's mobility by 100%. We enthusiastically recommend the Superarm Lift."
Mr & Mrs Crowl - Tulsa, OK

- **Fits full-size vans, RV's & some mini-vans *(ask us)***
- **Lifts Electric & Manual chairs *tell us if you have seat inserts***

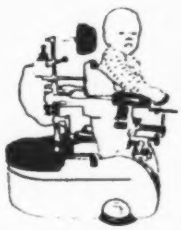
Visa and MasterCard accepted
Call or write for a free brochure

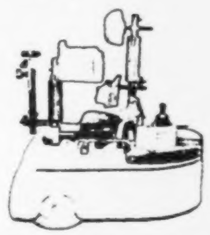
4335 So. Santa Fe Dr.,
Englewood, CO 80110
Fax. (303) 761-6811

1-800-782-4335
www.handicapsinc.com

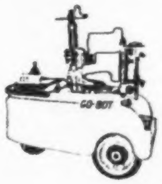
Circle #42 or visit www.eparent.com/adinfo

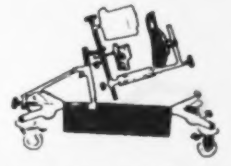
Early Childhood Mobility
Mini Go-Bot's





Century Stander Stanford Standard
Note*: *Standing frames work with either Go-Bot





Yellow Go-Bot
GB-I Gait Trainer
(can be customized)

Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com

Circle #46 or visit www.eparent.com/adinfo

ADVERTISEMENT

Universal Newborn Screening

In 1961, Dr. Robert Guthrie of the University of Buffalo developed a laboratory test to detect phenylketonuria (PKU) in newborns. PKU is an inherited metabolic disorder resulting from an enzyme deficiency; if left untreated, it results in profound mental retardation. In 1963 Massachusetts became the first state to mandate screening for PKU, which can be treated by lifelong dietary management and counseling. The National Association for Retarded Children (now The ARC), the Children's Bureau and the Kennedy Foundation were foremost among the organizations that pushed for widespread adoption of the Guthrie test, and by 1966 it was required for all children by all 50 states and the District of Columbia.

Dr. Guthrie and other researchers continued to develop newborn screening (NBS) tests to detect many more disorders, and each state decided what screens would be available for its newborns. Significant disparities resulted; in 1997, in Massachusetts, infants were tested for 10 or more disorders, while Utah's babies were screened for three. Montana and South Dakota each mandated three tests and offered one other by special request only. In the same period, with the introduction of ever-smaller and more powerful microprocessors, technology and equipment became significantly more sophisticated. This permitted testing that had not been feasible before. A process called tandem mass spectrometry (tandem MS, MS/MS) can now run tests for nearly 40 disorders at one time. None are curable, but all are treatable.

In the last two years, many states have expanded their NBS programs. Almost all Pennsylvania hospitals now offer the full spectrum of testing, although the law mandates testing for only six. Massachusetts routinely screens for more than 15 disorders and is running a pilot program offering 30+ tests. Wisconsin has almost tripled availability, from 7 tests to 20. Yet universal NBS still engenders much controversy, and there are many issues to be resolved before consensus can be reached on how the US will move forward.

The data tells us that of the four million babies born in the US each year, ten to twelve thousand may have one or more of these detectable...and treatable...disorders

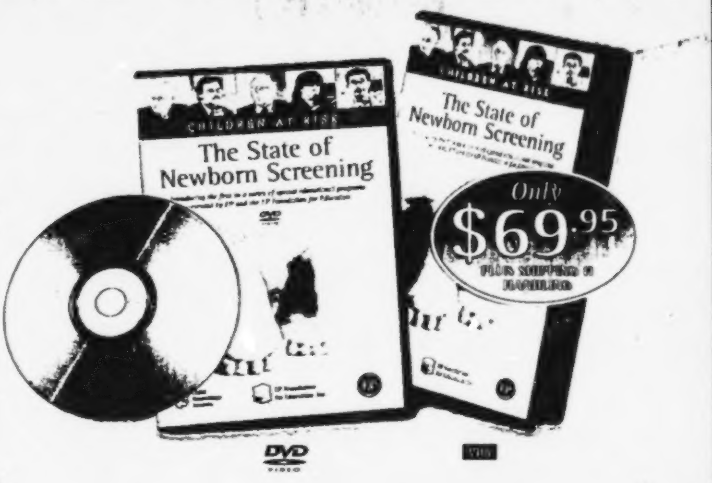
ISSUES: These may be economic, political, professional, sociocultural, religious. Capital spending, training, payment policies, long-term follow-up; insufficient hard financial data; union issues; professional knowledge levels and practice habits; citizen knowledge, and cultural and religious beliefs and practices; insurance, managed care companies, Medicaid, ChIP programs, the uninsured–all these and many more must be part of discussions and resolution.

With the current system, a child born in Louisiana with galactosemia will likely live a life marked by mental retardation and other special health care needs, while similarly affected children born the same day in most of the rest of the country will receive immediate treatment and become productive members of society. The data tell us that of the four million babies born in the US each year, ten to twelve thousand will have one or more of these detectable disorders, an almost-negligible number. The overall cost or benefit to our society, though, will vary wildly from one child to another because of the patchwork of screening availability. We as a nation must find a way to embrace universal NBS and make it routine for all children born in the US. More than that, it is downright wrong not to do so when it has proven its worth time and again!

It is a question of education and awareness. Research shows that the average couple planning to have children does not know anything about existing screening programs, much less the capabilities offered by tandem MS, largely because OB/GYNs, pediatricians, genetic counselors and related professionals are not familiar with universal NBS. The education gap relates to professionals and consumers, rich and poor, people of every race, religion and ethnicity. Few people know much about any of the issues. Worse, among the people who do profess knowledge of NBS and the issues, a good deal of what they "know" is wrong.

The information you need on Newborn Screening is finally available on DVD and video

Children at Risk:
The State of Newborn Screening
is now available on DVD and VHS. Introducing the first in a series of special educational programs presented by EP and the EP Foundation for Education, Inc., a 501(C)3 Not For Profit Corporation.



EP Foundation for Education, Inc. Child Neurology Society

Newborn screening can detect up to 39 metabolic disorders from one blood spot. All are treatable when diagnosed at birth, offering the chance for a full and productive life.

Leading medical and scientific professionals are gathered to provide the most current information available. You can view this valuable resource at your convenience and the DVD is indexed so that key topics are easily accessible.

Darryl DeVivo, MD
SIDNEY CARTER PROFESSOR OF NEUROLOGY
COLUMBIA UNIVERSITY

Piero Rinaldo, MD, Ph.D.
DIRECTOR, BIOCHEMICAL GENETICS LABORATORY
MAYO CLINIC

Edwin Naylor, Ph.D.
PRESIDENT
NEOGEN SCREENING, INC.

Joan E. Pellegrino, MD
ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES
UMDNJ ROBERT WOOD JOHNSON MEDICAL SCHOOL

Paul M. Fernhoff, MD
MEDICAL DIRECTOR
EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #44 or visit www.eparent.com/adinfo

familiar faces

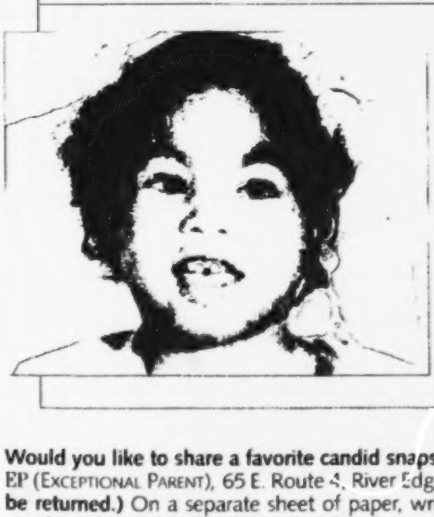
CONNOR

Connor Stueckle cools off on his sixth birthday—a hot one—splashing in the fountain at the Seattle Center. Connor has gross and fine motor delays, sensory integration dysfunction and is non-verbal. He loves the water, swinging with his dad, watching videos, riding on extreme roller coasters and visiting his Grandpa.

ANTHONY

Anthony Paul Pratti, 3, loves to watch Elmo videos and play on the computer. He rides the bus to preschool where he receives occupational, physical and speech therapies. Anthony, who was born with spastic quadriplegic cerebral palsy and autism spectrum disorder, garnered medals in two "Kid's Classic" races. "Nothing stops my little man," his mother proudly writes.

MAYA



Maya Vega, 3, loves the Teletubbies, music and babbling. Maya has developmental delays, seizures and cerebral palsy. Her mom and dad, Idaliz and Ray, write that Maya is the most huggable little girl and they could hug her all day long.

MICHAEL

Michael Arechavala, 3, loves playing with his brother, Kevin, 9, and sister, Michelle, 5. Michael has Down syndrome, and attends a fully inclusive preschool all week where he receives OT, PT and speech therapy. He enjoys going to the playground, eating ice cream and hanging out at the beach.

JAKE

Jake Alan Hetrick, 5, and sister, Eliza, 2, have a great time together. Just like a typical older brother, he laughs when she gets into trouble! Jake has cerebral palsy, cortical blindness and has microcephally. He survives his twin, who died in utero from twin-to-twin transfusion syndrome. He attends preschool during the week and a special needs Sunday school class. His favorite things are music, ice-cream and swimming.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (EXCEPTIONAL PARENT), 65 E. Route 4, River Edge, NJ 07661. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

738

As our volunteer clearly demonstrates, 21* pediatric medical journals can be quite difficult to digest.

In fact, unless you have a medical degree we wouldn't recommend it.

If you have an interest in the latest breakthroughs and research published in pediatric journals, but don't have the medical training required to easily digest the information, there is an alternative.

ChildHealthMonitor.org publishes articles adapted from the latest monthly issue of each of the world's leading pediatric publications*. The information is the same. The difference is that much of the medical jargon is replaced with everyday language. It's also online which means that anyone with an Internet connection can now have instant access to reliable, useful information on the latest advances in treatment, prevention, and caring for kids.

Simply, visit **www.childhealthmonitor.org** and you too can have unlimited access to hundreds of simply written articles on up-to-the-minute pediatric discoveries.

We think you'll find this option much more palatable. (Our volunteer did.)

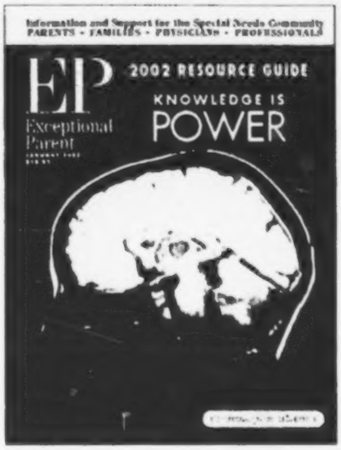
CHM

ChildHealthMonitor.org

* Acta Paediatrica, Archives of Disease in Childhood, Archives of Pediatrics and Adolescent Medicine, Brain and Development, British Medical Journal, Child: Health, Care and Development, Developmental Medicine and Child Neurology, European Journal of Pediatrics, Journal of Adolescent Health, Journal of Child Psychology and Psychiatry, Journal of Paediatrics and Child Health, Journal of Pediatric Psychology, Journal of Pediatric Surgery, Journal of Pediatrics, Journal of the American Academy of Child and Adolescent Psychiatry, Journal of the American Medical Association, The Lancet, New England Journal of Medicine, Pediatric Infectious Diseases Journal, Pediatrics, and Research in Developmental Disabilities

EXCEPTIONAL PARENT LIBRARY

- ☐ Books for Parents, Children and Siblings
- ☐ Books for General Reading and Specific Special Needs
- ☐ Information That You Need: References, Practical Guidance, Coping and Caring.


Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS
EP
Exceptional Parent
2002 RESOURCE GUIDE
KNOWLEDGE IS POWER

2002 Annual Resource Guide
Available Through
EP Library $19.95

All selected by the Editors of Exceptional Parent magazine.

FOR A COMPLETE BROCHURE AND DISCOUNT COUPON (GOOD TOWARDS YOUR FIRST PURCHASE)

Order On Line: www.eplibrary.com
or Call: 800-535-1910

Announcing A Special Offer From EP Press

Patient Persistence

Adele M. Gill

Patient Persistence

ON SALE NOW! This book celebrates the ability of people to overcome obstacles to achieve their goals. The author, Adele Gill, is a certified disability analyst, a Fellow of the American Board of Disability Analysts, and an advocate of inspirational and motivational self-help. Ms. Gill has divided the book into two sections, Hope and Courage. Both contain selections that deal with turning points in people's lives, times when they found strength, hope, and the courage to persevere in the face of adversity. This book offers help and hope to those who feel that their lives are out of control or that things have gotten so bad that there will never be a way to make them better. Through examples from the lives of real people, this volume demonstrates that there is always a way.

Code # EP8004GN ~~Price $19.95~~ **Sale $15.95**

No Apologies for Ritalin

Vidya Bhushan Gupta, MD

NO APOLOGIES FOR RITALIN

ORDER NOW & SAVE! This book takes an in-depth look at attention deficit disorder/attention deficit hyperactivity disorder (ADD/ ADHD). Vidya Bhushan Gupta, MD, MPH, a Board-certified pediatrician and a Fellow of the American Academy of Pediatrics, is Director of Developmental-Behavior Pediatrics at Metropolitan Hospital Center, New York City. In his book, Dr. Gupta eloquently educates parents of children with ADD/ADHD about the disorder and available treatments, so that they can make informed choices for the care of their children. The first portion of the book describes what is medically known about ADD/ADHD, including causes and diagnostic methods; the second part outlines available treatment options, including Ritalin and other drugs, dietary changes, herbal therapy, and behavior modification. Dr. Gupta's purpose is to help parents of children with ADD/ADHD to stop blaming themselves for their child's disorder and to investigate and use appropriate therapies, including Ritalin and other medications when indicated, without guilt.

Code # EP8012AD ~~Price $19.95~~ **Sale $16.95**

These books are published by EP Press, the book publishing division of Exceptional Parent magazine, the country's oldest and most widely read publication for families of children and adults with disabilities and special health care needs and the physicians, allied health care professionals and special education teachers involved in their care and development. **For a limited time these books can be ordered at this special price by calling EP Library at 800-535-1910, or through their web site at www.eplibrary.com. Use coupon code: EP06015P**

circle #

740

The Window of the Body: Oral Signs of Systemic Disease

by Michael A. Kahn, DDS, and Jerry E. Bouquot, DDS, MS

The mouth has often been called the barometer of a person's health. Serious illnesses, conditions or genetic disorders may first present with mouth conditions such as unusual bleeding or multiple lumps and bumps in the mouth, extra or missing teeth or their premature loss. These mouth changes are frequently helpful in determining the underlying disease or its cause.

Unusual Bleeding in the Mouth

There is a wide range of diseases or conditions of the human body which may first be detectable, or whose diagnosis can be confirmed, by signs of bleeding within the mouth. The diseases or conditions that can affect children and teenagers include infectious mononucleosis, measles, hemophilia, leukemia, and vitamin deficiencies, particularly vitamins C and K.

Infectious mononucleosis ("mono" or " kissing disease")

Children usually become infected with the Epstein-Barr virus (EBV) that causes mono through saliva contaminated with EBV on fingers, toys, or other objects. Teenagers usually get EBV through direct transfer of saliva, such as shared straws or kissing. In the United States, it is estimated that approximately half of the population is exposed to EBV by college age.

Children less than four years of age typically experience fever; swollen, tender neck glands; sore throat; liver and spleen enlargement; runny nose or cough. Older children have similar symptoms but less often have an enlarged liver and spleen, runny nose and cough. In the mouth, the tonsils may be enlarged and may have pus on the surface. One can sometimes observe tiny bleeding spots on the roof of the mouth during the first day or two of the infection. The gums may also get red, sore, bleed and have a foul smell. Diagnosis can be confirmed by special laboratory tests.

Measles

Measles is an infection caused by a virus (paramyxovirus) that presently occurs only in children who are not given the available measles vaccine or, in rare instances, when the vaccine fails. Most cases start in the spring and are spread through contact with someone who has the infection and sneezes or coughs near them. The typical skin rash appears after symptoms of fever, lack of energy, runny nose, red eye and a cough.

The most distinctive early mouth sign of measles is Koplik spots on the lips, cheeks and roof of the mouth. These are numerous, small blue-white flat growths that look like grains of salt. Other mouth findings include a white yeast infection that can be rubbed off and bleeding, foul-smelling gums. The tonsils may also look enlarged. Developing adult teeth can be affected so that when they appear in the mouth they show pits and small holes in the

continued on page 101

Getting information from

EP advertisers is

MUCH FASTER

ONLINE!

It's as easy as a click
of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers

CLICK!

For quick, easy access
to our advertiser's
websites use: www.eparent.com/adinfo

742

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in Exceptional Parent.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.

Be sure to tell them you saw their ad in Exceptional Parent!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
17	ABILITIES EXPO	79
22	ADAPTIVEMALL.COM	42
18	ALTIMATE MEDICAL	77
19	ANNANDALE VILLAGE	33
20	ANNE CARLSEN SCHOOL	51
23	BODYPOINT DESIGNS, INC.	39
24	CAMPHILL SPECIAL SCHOOL	115
	CHILDHEALTH MONITOR	95
25	CHILDREN'S HOSPITAL	45
26	COLUMBIA MEDICAL	67
27	CONNETQUOT WEST	56
28	COTTING SCHOOL	88
29	CROTCHED MOUNTAIN REHABILITATION	52
30	CYBERONICS, INC.	8-10
	CYCLETOTE CORP.	60
31	DANMAR PRODUCTS	69
32	DRIVE MASTERS	42
33	DURALIFE, INC.	78
34	DYNAVOX SYSTEMS LLC	31
35	EDEN FOODS, INC.	4
200	EP LIBRARY PAGES	110-111
44	EP NEWBORN SCREENING DVD	92-93
199	EP SUBSCRIPTION CARD	17-18
45	EP TELECONFERENCE	7
36	EQUIPMENT SHOP	32
37	EVERGREEN CENTER	78
38	FORD MOBILITY	C2
39	FREEDOM MOTORS USA	36
40	GLOBAL POWER SYSTEMS INC.	61
41	H.D.I.S.	34
42	HANDICAPS, INC.	91
43	HARD MANUFACTURING	16
21	HEARTSPRING	35
	HOUSE AD	85, 98
46	INNOVATIVE PRODUCTS	91
47	KENNEDY KRIEGER	71
75	KIMBERLY CLARK	53
48	LAWYERS, INC.	63
49	LINCOLN CTR FOR PERFORMING ART	11
50	LITIGATORS, INC.	37
51	MATHENY SCHOOL & HOSPITAL	86
52	MELMARK	47
53	METROPOLITAN LIFE INS.	57
	NEW ENGLAND VILLAGE	32
54	OCEAN HYPERBARIC CENTER	87
55	OTTO BOCK	C3
56	REAL DESIGN	48
57	RED BARN ENTERPRISES	61
58	ROCK N ROLL CYCLE	88
59	ROSS LABORATORIES	23
60	SAMMONS-PRESTON	15
61	SIGMA TAU	1-2
62	SNUG SEAT INC.	19
63	SOUTH FLORIDA CENTER FOR HOPE	21
	ST. LOUIS CHILDREN'S HOSPITAL CONFERENCE	81
64	STEWART HOME SCHOOL	56
65	THE BABY JOGGER COMPANY	21
66	THE CENTER FOR DISCOVERY	49
67	TORONTO HYPERBARIC INC.	43
68	ULTRAFLEX SYSTEMS, INC.	11
69	VAIL PRODUCTS	C4
70	VERIZON	3
71	WOODBURY PRODUCTS	89
72	WORLD CONGRESS	24-27

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

EP

has the information an "Exceptional Parent" like you needs

EP Exceptional Parent

Subscribe on our website: www.eparent.com

and save $5.00

For telephone orders call:

877-372-7368

To start your subscription to EP today, fill out the card near the front of this magazine or log on to www.eparent.com

EXCEPTIONAL PARENT Free product & service information order card* JUNE 2002

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ____________________
Address ____________________
City ____________ State ______ Zip ______
Phone ____________ Fax ____________
E-mail ____________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No
If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist ^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist
^{10}☐ Other (please indicate) ____________

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No
If Yes, are you a: ^{13}☐ Other (please indicate) ____________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No
If yes, please explain ____________

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

*CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: November 30, 2002

BJUN2

EXCEPTIONAL PARENT Free product & service information order card* JUNE 2002

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ____________________
Address ____________________
City ____________ State ______ Zip ______
Phone ____________ Fax ____________
E-mail ____________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No
If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist ^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist
^{10}☐ Other (please indicate) ____________

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No
If Yes, are you a: ^{13}☐ Other (please indicate) ____________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No
If yes, please explain ____________

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

*CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: November 30, 2002

BJUN2

743

To start your subscription to EP today, fill out the card near the front of this magazine or log on to
www.eparent.com

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage Necessary if Mailed in the United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage Necessary if Mailed in the United States

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer lif for themselves and for their children.

Exceptional Parent's MISSION IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS
Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

continued from page 97

enamel. Diagnosis is usually straightforward, based on the patient's symptoms and knowledge that measles is "going around." For a single or unusual case special laboratory tests are available.

Hemophilia

Hemophilia is a group of bleeding problems associated with a genetic lack of one of the clotting elements of the blood. The most famous historical cases are male children of the European royal families, many of whom died from a direct result or complications of uncontrolled bleeding. Presently, blood transfusions and replacing the missing clotting element spare many lives. Since hemophilia A (lack of blood factor VIII) is the most significant and common type it will be the only one discussed here.

Hemophilia A is known as a genetic X-linked disorder; females may have the defective gene, but the disease is almost always seen only in males.

Hemophilia A is known as a genetic X-linked disorder; females may have the defective gene, but the disease is almost always seen only in males. Failure of normal clotting after circumcision is typically one of the first signs that a bleeding disorder is present. The outward signs and symptoms vary from mild bleeding problems to severe, life-threatening bleeding. In toddlers, oral cuts or bruises from falls and bumps may result in significant blood loss. Even normal physical activity may result in internal bleeding of the skin (deep bruising), muscles and large joints such as the knee or elbow. Scar formation often results, causing crippling deformities of the joints. Sometimes, a tumor-like growth forms in the body or within the mouth. Routine dental treatment such as cleaning teeth may result in uncontrollable or delayed bleeding. Blood clotting screening (nonspecific) tests should be ordered for any child suspected of having this or other bleeding disorders.

Leukemia

Leukemia may affect both children and adults. For unknown reasons thought to be genetic and environmental, a stem cell in the bone marrow becomes cancerous as it develops, multiplying rapidly and preventing the marrow from making enough red blood cells, white blood cells or platelets. Leukemia can be classified into acute or chronic types with several subdivisions. Acute leukemias, if untreated, run an aggressive course and often result in the death of the patient within several months. Chronic leukemias usually run a milder course although, without treatment, the patient will also die. Certain genetic disorders or syndromes present an increased risk of developing leukemia. In addition to Down syndrome, these include such rare syndromes as adult Bloom syndrome, Schwachman syndrome, ataxia-lymphoma syndrome Klinefelter syndrome, Fanconi's anemia and Wiskott-Aldrich syndrome.

Many of the signs and symptoms of leukemia are related to the significant reduction of white and red blood cells. Because there are fewer red blood cells that carry oxygen throughout the body, patients complain of no energy, easy tiring and shortness of breath upon mild physical activity. The cancerous cells can invade organs, such as the liver and spleen, and cause the lymph nodes to enlarge. Patients with leukemia may demonstrate easy bruising and bleeding resulting from the lack of blood platelets. Tiny bleeding points on the roof of the mouth may be seen, along with bleeding from the gums for no apparent reason. Deep mouth ulcers often appear, usually affecting the gums most severely. A widespread oral yeast infection is common, as are cold sores (fever blisters). Occasionally leukemic cells invade gum tissue, resulting in a widespread, boggy, nontender gum enlargement. Finally, the bone around the bottom of the tooth's root can become infected, causing a toothache.

Vitamin C and K deficiencies

In the US, significant vitamin deficiencies are uncommon. Children with malabsorption (food nutrients do not get into the blood) or eating disorders, teenagers who follow fad diets and people who have alcoholism are the groups most commonly affected. Vitamin C (ascorbic acid) is necessary for the proper formation of collagen, the major protein of cartilage, bone and connective tissue. This vitamin is present in a wide variety of fruits and vegetables and is especially abundant in citrus fruits such as oranges and grapefruit. Vitamin K is necessary for the proper formation of various proteins, including those involved in clotting. Vitamin K is present in a wide variety of green vegetables and is produced by intestinal bacteria.

In the US, a deficiency of vitamin C—scurvy—is usually limited to those peo-

continued on page 102

ple who lack an adequate diet of fresh fruits and vegetables. One of the commonly-affected groups is inner-city infants whose diet consists entirely of milk. The outward signs are related to a lack of collagen formation. For example, weakened blood vessel walls may result in the formation of bruises in the mouth. Wound healing is delayed and recently-healed wounds may break down. Children are particularly susceptible to painful bleeding just above the bone surface. Within the mouth, generalized gum swelling with spontaneous bleeding is observed, as are ulcers, loose teeth and loss of bone around the teeth. Untreated scurvy can lead to death from bleeding within the brain.

Insufficient vitamin K causes a lack of blood-clotting elements that result in gingival (gum) bleeding for no apparent reason.

A lack of vitamin K may be seen in patients with malabsorption problems or in those whose intestinal bacteria have been eliminated by long-term use of broad-spectrum antibiotics. Oral blood thinners such as coumadin also reduce the normal activity of vitamin K. Insufficient vitamin K causes a lack of blood-clotting elements that result in gingival (gum) bleeding for no apparent reason. If uncorrected, death may result from uncontrolled bleeding.

Multiple Lumps or Bumps in the Mouth

Some common and uncommon diseases and conditions of the body are revealed by a display of generalized or individual multiple lumps or bumps (lesions) in the mouth. The tongue is a favorite site for these lesions; they may be exhibited at birth or in childhood in at least seven genetic diseases. Other conditions causing childhood lumps and bumps in the mouth include Crohn's disease and tuberous sclerosis.

Enlarged Tongue

An enlarged tongue most commonly occurs in children and can range from mild to severe. In infants, it may be manifested first by noisy breathing, drooling and difficulty in eating. In young children a lisp may develop, along with an open bite and a jutting lower jaw. If the tongue constantly sticks out from the mouth, it may develop sores, become infected and may even start to break down. Diseases that cause enlargement of the tongue from multiple lesions include Down syndrome and rare conditions such as hypothyroidism, Beckwith-Wiedemann syndrome, the mucopolysaccharidoses (MPS), multiple endocrine neoplasia syndrome type 2B (MEN 2B) and neurofibromatosis (von Recklinghausen's disease of the skin). In patients with hypothyroidism or Beckwith-Wiedemann syndrome, the tongue usually has a smooth generalized enlargement. The other listed conditions typically have multiple, separate bumps and lumps.

Hypothyroidism is caused by decreased levels of thyroid hormone in infancy; typically the patient exhibits lack of energy and fatigue; cool, dry, rough skin; swelling of the face, arms, and legs; huskiness of the voice; constipation and weakness. Not all of these signs might be readily apparent in the infant and a failure to grow normally might be the first indication of the disease. The general enlargement of the tongue results from an accumulation of certain substances in the deeper layers of the tongue; the lips may also appear thickened. The baby teeth and, later, the adult teeth may fail to erupt, although those that do appear normal. Abnormal thyroid hormone levels will confirm the suspected condition.

Beckwith-Wiedemann syndrome is a rare genetic disease that includes protrusion of part of the gut through the navel, enlarged organs such as the spleen and liver, increased height and the onset of diabetes within the first 30 days after birth. Affected children are more likely to get certain body organ tumors. The face may have a large reddish birthmark that covers the forehead and eyelids; the upper jaw tends to be underdeveloped. The main finding in the mouth is the overall tongue enlargement.

Down syndrome, caused by an extra gene located on chromosome 21, may result in mental retardation and many physical signs, including a flat face with a short nose, protruding lower lip, small rounded ears, loose joints, wide hands and feet, stubby fingers, extra neck skin and a lack of muscle tone in newborns. In the mouth, a common finding is a thick, enlarged tongue with numerous surface fissures (deep grooves). Teeth may be smaller than normal and either too many or too few. Genetic tests will confirm the diagnosis.

The mucopolysaccharidoses are very rare genetic diseases in which one of several enzymes, and thus an important group of tissue building blocks, is missing. Most types of MPS display some degree of mental retardation. Often, the affected person has pronounced features. Other symptoms may include stiff joints and cloudy corneas. There may be varying degrees of tongue enlargement. Other mouth findings include enlarged gums (especially in the front) and abnormally shaped crowns with pointed tips on the back teeth. In other forms of the disease, teeth do not erupt through the gums. Diagnosis is confirmed by laboratory tests.

Multiple neoplasia syndrome, type 2B (MEN 2B) is one of a group of rare genetic conditions characterized by tumors of the pancreas, adrenal glands, parathyroid/thyroid glands and the pituitary gland. In MEN 2B, the child or young adult will often develop thyroid cancer, adrenal tumors, and multiple bumps or lumps within the mouth. Patients usually have thin, long arms/legs with muscle loss. The face is narrow but the lips are thick and jut out. The upper eyelid is sometimes inside out and small bumps may be present on the eyelid. The first sign of the condition is multiple bumps in the mouth, most commonly on the tongue. The mouth bumps and those of the lips and eyes are actually benign nerve tumors that may appear on the inside of the cheeks, the gums, roof of the mouth and, commonly, at both corners of the mouth. Laboratory and genetic test values are necessary for a final diagnosis.

Neurofibromatosis is a relatively common genetic condition. Although there are at least eight different forms of the disease, the most common type is von Recklinghausen's disease of the skin. Patients exhibit multiple skin bumps that are usually harmless nerve tumors. The bumps may be present at birth but become much more numerous after puberty. They may get extremely large; the exact number of bumps varies greatly among patients. Another characteristic feature is the presence of colored spots on the skin that have been described as having a "coffee-mixed-with-milk" color. They are usually present at birth or appear during the first year of life. Freckles in the armpits are another common sign. The irises may have brown spots. Some patients may also develop brain tumors, mental retardation, seizures and curvature of the spine. In the mouth, it is common to find multiple bumps (nerve tumors) on the tongue with an increased roughness of the tongue surface. X-ray films of the jaws may show characteristic changes. Diagnosis is made from the presence of two or more of seven characteristic physical findings.

Some patients have enlarged gums as a side effect of medicine taken for seizures; others will have defects in the jaws that can be seen in X-rays.

Granulomatous diseases

These conditions have a common feature, a characteristic type of inflammation with a special appearance under the microscope. Within this group of lesions, Crohn's disease typically has its onset during the teenage years.

Crohn's disease is an inflammatory condition of unknown cause that mainly affects the end of the small bowel and the beginning of the large bowel, although it may involve the entire gastrointestinal system. Other sites that may be affected include the skin, eyes and joints. Approximately 30 percent of the time, the mouth signs appear before the stomach and bowel lesions. The gastrointestinal involvement leads to complaints of abdominal cramping and pain, nausea and diarrhea. Weight loss and malnutrition may develop, which can lead to decreased red blood cells and decreased growth.

Many different types of mouth lesions have been observed in Crohn's disease. The more common are multiple or separate bumps of the mouth and lips, a so-called cobblestone appearance of the mouth lining, and deep ulcers or holes, especially of the area beneath the gums. Biopsy of the gut lesions and the person's symptoms lead to a correct diagnosis.

Tuberous sclerosis (Bourneville-Pringle syndrome) is uncommon and classically displays mental retardation, seizures and angiofibromas, specific growths on the face. Besides cases of familial origin, this condition can be caused by random, unexplained genetic mutations.

Angiofibromas occur mainly in the crease of tissue next to the nose. Similar bumps can be found next to or under the fingernails. Other types of skin lesions are seen, including a focal area that has a rough surface or that lacks normal skin color. Some patients develop a heart tumor; others may have tumors in the kidneys.

In the mouth, the enamel of the front teeth is often pitted. Another common finding is multiple small bumps on the front gums; they may also be displayed on the lips, inner cheeks, roof of the mouth and tongue. Some patients have enlarged gums as a side effect of medi-

continued on page 104

continued from page 103

cine taken for seizures; others will have defects in the jaws that can be seen in X-rays. The appearance of the patient establishes the diagnosis.

Extra or Missing Teeth, or Premature Loss of Teeth

• Extra teeth

Extra teeth may be present when the child is born with a cleft lip and/or a cleft palate. One example is cleidocranial dysplasia, a rare genetic bone disorder whose most outstanding characteristic is the absence of a collarbone or one that is deficient on one or both sides. The child tends to be short, with a characteristic facial appearance of wide spaced eyes and prominent forehead. In the mouth, the roof is often narrow and high and cleft palate is often seen. Various dental changes are exhibited. The baby teeth often do not loosen and the adult teeth are delayed in appearing or only partially come through the gum. Many extra teeth may form in the jawbones but fail to erupt into the mouth. X-ray pictures of the jaws will demonstrate characteristic changes besides the abnormal teeth. The diagnosis is based on the above-mentioned signs.

• Missing Teeth

One condition that exhibits missing teeth is hereditary hypohidrotic ectodermal dysplasia, the best known of a group of genetic conditions in which at least two derivatives of the ectoderm (teeth, hair, nails, glands) are deficient in function or absent altogether. Hereditary hypohidrotic ectodermal dysplasia occurs much more often in males. In infancy the baby appears to have an unexplained fever, but actually, the body temperature cannot be controlled in the normal fashion because of a lack or reduced number of sweat glands. Death can occur from this heat intolerance. Other signs include fine, sparse blond hair; this conditions affects not only the head but also the eyebrows and eyelashes. The lips may stick out, as the center of the face is often not fully developed. The nails are often brittle and defective. Within the mouth, there is a lack of saliva due to undeveloped salivary glands and the number of teeth is markedly reduced. The crowns of the teeth are abnormal and often have a cone or pointed shape. These features determine diagnosis.

• Premature loss of teeth

In addition to a traumatic event, jaw infection, or cancer chemotherapy, numerous diseases can result in a premature loss of baby or adult teeth. The list includes diabetes, chronic or cyclical loss of white blood cells, Papillon-Lefevre syndrome, Down syndrome, scurvy, dentin dysplasia, regional odontodysplasia, Langerhans cell disease, leukemia, AIDS and hypophosphatasia.

Hypophosphatasia, a rare, genetic bone disease, is characterized by a lack or reduced amount of alkaline phosphatase, a particular tissue enzyme that is thought to play a role in the production of bone. This disorder is usually diagnosed in infancy although it may not appear until later in childhood or even adulthood. The diagnosis is based on the clinical signs and laboratory tests.

The infantile form usually presents after 6 months of age, when the infant shows a failure to grow. Vomiting and lack of muscle tone may develop. Skeletal malformations reminiscent of rickets appear (e.g., shortened, bowed limbs). Kidney stones also form, as do rib and skull deformities. In the childhood form, a hallmark finding is the premature loss of baby teeth with no apparent infection. The upper and lower front four teeth are usually affected first and may be the only teeth involved. Sometimes the inside of the teeth appears abnormal on an X-ray and the bone around the teeth may be reduced. In X-rays, the skull has an abnormal appearance that has been described as "beaten copper"–it looks like a piece of metal that has been repeatedly hit with a hammer. This look is probably due to thinning of the skull's inner plate of bone.

View Through the Window

Inspection of the mouth, the "window of the body," and its supporting structures is often an excellent, simple way for doctors to identify not only localized dental and gum infections but more generalized body diseases, genetic disorders and conditions. The informed doctor or parent can utilize this information to identify possible serious health problems and to initiate appropriate treatment early, which may lead to a more favorable outcome with fewer complications for the patient. EP

Michael A. Kahn, DDS, is a Professor of Biologic and Diagnostic Sciences, and Director of the University of Tennessee Oral and Maxillofacial Pathology Diagnostic Services. He is a Fellow and Councilor of the American Academy of Oral and Maxillofacial Pathology and a Diplomate of the American Board of Oral and Maxillofacial Pathology. He is also a charter member of the UT Health Science Center's Academy of Distinguished Teaching Professors.

Jerry E. Bouquot, DDS, MS, is Director of Research of The Maxillofacial Center for Diagnostics & Research and also Director of Head & Neck Diagnostics of America, Morgantown, WV. He is a Fellow of the American Academy of Oral and Maxillofacial Pathology and a Diplomate of the American Board of Oral and Maxillofacial Pathology. He is also a Professor of Dental Medicine at Capital University School of Integrated Medicine, Washington, DC.

Special Report

Part 1. The Beginning: How Parents Move Forward and Make Choices After Diagnosis

By Elizabeth King Gerlach

This is the first in a series of articles designed to address the issues that parents and families have to face as they strive to meet the needs of their children with lifelong disabilities.

Shared Perspectives

As parents of children with disabilities, when we stand side by side with a teacher, a doctor, a therapist or even a family member, we see our child differently from the way they do. Our children touch every place in our hearts. We see the child in relation to our whole life, a reflection of our dreams for them and for ourselves. We will be their lifelong advocates, caregivers and friends.

Because every individual and family has unique circumstances, each vision and journey will differ; but as parents of children with disabilities we have common ground. So much understanding can be gained by sharing stories and perspectives of other parents. We can help each other embrace the enormous changes that begin when we learn our child has a disability and support each other as we cycle from grief to action and discover new opportunities for our children and ourselves.

Getting the News

Not all of us get the news that our child has a disability at the same stage. Some of us receive it at birth, others when their formerly "normal" child experiences a life-altering accident. Still others learn it gradually, as their child misses certain developmental milestones and is later diagnosed as having a developmental delay.

No matter how severe or minor the disability, the shock of discovery and the cycle of emotions are universal. Scott Felsher's son was born with a clubfoot and also had difficulty breathing at birth. Scott recalls, "Looking back, it makes me realize what a normal human reaction it is to experience shock when you are faced with a physical abnormality. I would watch all the different nurses come through the unit and look at his chart. They would almost all lift up the blanket and look at his foot first. That tiny, infant foot might as well have been the size of Rhode Island. It hurt to see my beautiful baby boy and think that people would see his disability before they would see him." While clubfoot is not as severe a disability as many parents must face, Scott experienced the wide range of emotions most of us feel when we get the unexpected news of disability: shock, anger, sadness, denial, grief.

The composite wisdom of many parents also attests to the benefit of these general steps in moving from awareness to resolution:

- ○ Allow time to heal and time to grieve. Be patient with yourself.
- ○ Ask for help and support from people you trust who are good listeners.
- ○ When you are ready, contact local disability support groups through their national offices. Early interventionists or school counselors can also often provide contact information. It helps to know you are not alone.
- ○ Speak with other parents as well as experienced professionals such as family therapists, physicians, social workers, special education professionals, school mental health specialists and clergy.
- ○ Establish routines and engage in healthy behaviors; eat well and get enough rest.

continued on page 106

INFORMING

EMPOWERING

Finding the right educational setting for their child with special needs is among the many challenges faced by parents.

AND KEEPING PARENTS INVOLVED

THIS SERIES IS MADE POSSIBLE BY AN UNRESTRICTED EDUCATIONAL GRANT FROM THE INTERNATIONAL FAMILY INSTITUTE AT THE CENTER FOR DISCOVERY IN HARRIS, NEW YORK. WWW.DISCOVERYIFI.ORG - WWW.THECENTERFORDISCOVERY.ORG

[illegible] 749

continued from page 105

"There are three basic components to processing emotions: awareness, expression and resolution," says Zack Schwartz, PhD, a clinical psychologist with a private practice in Oregon. "It is important to understand and interpret your feelings and then develop healthy outlets for them. Such outlets might include conferring with a confidante or exercising or expressing your feelings through artwork."

Other children in the family will also benefit from support during this initial phase. Siblings might feel confused, concerned or even left out. In addition to seeking professional advice, resourceful parents can help siblings adjust by keeping the lines of communication open, by finding time to spend alone with each of their children, and by involving them directly in the process as an advocate for their sibling and a teacher for other children.

Many organizations also offer general tips on helping siblings deal with their emotions. Good ones include the Sibling Support Project at the ARC web site and the Parent Advocacy Coalition for Educational Rights Center (PACER) (see Resources). Books for children, like *Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs* (Woodbine House, 1997) and *Living with a Brother or Sister with Special Needs: A Book for Sibs* (University of Washington Press, 1996) can help siblings understand what other kids have been through. Of course, books for parents are indispensable, too (See Additional Reading).

Moving Forward

After the initial shock and uncertainty of learning the news our child has a disability, we must learn all we can about the disability so that we can make informed choices on the multiplicity of issues that will arise. These might include what therapies and procedures are necessary, what insurance will cover and what support services are available. By educating yourself about your child's disability, you will gain confidence in dealing with these issues. Still, it can feel like an uphill climb.

Purnima and Ruben Hernandez live in New Jersey with their son, Naryan, age 4, and their daughter, Sophia, age 2. Born three months premature, Naryan weighed a scant one pound. His six-month stay in the NICU encompassed treatment for his multiple infections, gastrointestinal and brain-related issues and many procedures, including laser eye surgery and spinal taps. He has since been diagnosed with autism and other developmental delays.

From the day Naryan was born, it was clear that his care was going to be an expensive endeavor. Purnima recalls: "When money issues arise then the battle begins with everybody. The fight has been constant on the medical and insurance front. Sometimes you are made to feel like a criminal or a wrong-doer, or as if you are to blame for the child's disability." In her experience, Purnima feels that gathering as much information as possible is the best step a parent can take to keep on top of the different aspects of medical care and insurance and to make informed choices. She notes: "As the disabilities are discovered we do complete research on what the issue is. We then analyze it and the options. As parents, we feel that we have to take a lead role in Naryan's recovery."

ADDITIONAL READING

Changed By a Child, by Barbara Gill (Doubleday, 1998).

The Child With Special Needs: Encouraging Intellectual and Emotional Growth, by Stanley Greenspan (Perseus Press, 1998).

A Difference in the Family: Living with a Disabled Child, by Helen Featherstone (Viking Press, 1981).

From the Heart: On Being the Mother of a Child with Special Needs, by Jane B. Marsh (Woodbine House, 1995).

Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability, by Robert A. Naseef (Paul H. Brookes, 2001).

Uncommon Fathers: Reflections on Raising a Child with a Disability, by Donald J. Meyer (Woodbine House, 1995).

When God Doesn't Make Sense, by James Dobson (Tyndale House, 2001).

Information can be gleaned from many sources, including parents of other children with disabilities. MUMS: National Parent-to-Parent Network matches parents of children with similar disabilities. Beyond parent networks, an array of organizations offer resources, information and links. The Center for Discovery's International Family Institute Web site offers links to advocacy and legal resources, assistive technologies, early intervention, news services and magazines, government, medical information and more. The National Information Center for Children and Youth with Disabilities (NICHCY) provides good general information on a wide variety of disabilities.

Many parents have found it useful to establish a file system devoted to their child in order to keep track of the important papers and information that quickly accumulate. You can arrange separate folders for insurance claims, correspondence, individual doctors, therapists and direct support professionals (DSPs), education-related issues and other general information. Also invaluable is a separate binder or folder devoted to information on your child's specific disability, which can be readily duplicated and distributed to caregivers, teachers and friends. Day-timers, calendars or personal electronic organizers can help keep track of appointments and treatment intervals. A pocket-size electronic or print diary is also helpful for keeping track of daily observations and questions and for jotting down questions or insights to share with professionals.

Sometimes, among the mass of information and opinions from family, friends, and professionals, it is difficult to remember the significance of one's own wisdom and instincts. Purnima Hernandez stresses the importance of listening to one's inner voice alongside all the other voices: "Parents are given this amazing gift of instincts along with their child at birth, instead of a manual. To use it is your choice."

The Pondolfino family—Scottie, Jackie and Zachary in front of mom, Michele and dad, Jerry.

Navigating the Education System

After health and care concerns, achieving the appropriate education for their young child is often the greatest concern parents have. Fortunately, parents today have far greater options than ever before. Federal legislation called the Individuals with Disabilities Education Act (IDEA) mandates that children with disabilities be provided with a free and appropriate public education and related services from birth to age 21 years. Understanding IDEA and the rights and options it gives to your child will be a powerful tool as you negotiate decisions that will have a direct effect on your child's life.

IDEA identifies two stages of service for children, depending on their age. For children ages birth to 3, IDEA specifies that an Individual Family Services Plan (IFSP) must be developed to integrate multiple services for the child and the family. The IFSP is tailored to the needs of each particular child and could include family training, case management services speech, occupational and/or physical therapy services, and other options. Under IDEA, each state is required to have an Early Intervention Program. The National Early Childhood Technical Assistance System (NECTAS) is an excellent source for information on Early Intervention Services available nationwide (see Resources).

Under the law, children ages 3 to 5 years must be provided with the same services that their school district provides for school-age children who qualify for special education services. IDEA mandates that once a child enters school, a written plan called an Individualized Education Program (IEP) must be in effect within 30 days after the child has been evaluated and determined eligible for special education services. An IEP is developed by a team of educational and other specialists in coordination with the parents and in accordance with the unique needs of the child. It should be updated yearly. These updates provide focused opportunities for adjustments or modifications that reflect the child's evolving abilities and needs. Regrettably, there is no nationwide standard for the adequacy of special services for children; so the quality of services can vary tremendously from state to state and even between school districts.

Unique Children, Unique Choices

Even with all these protections, navigating the educational process and deciding which choices are right for your child can still be daunting. There is no set formula, no predetermined path. We can gather information and advice, but often we must simply try one avenue and see if it is appropriate or successful. Children and situations change, and raising a child with special needs requires not only diligence, but also flexibility. If your child's services are not meeting his or her needs or the needs of your family, you may need to pressure your school district to provide an adequate program. Sometimes the help of an attorney or an experienced educational advocate is necessary if agreement cannot be reached in an amicable manner.

My own son, Nick, now 16, was diagnosed with autism at age 4, although he showed signs of his disability from age 2. Our choices for him have run the gamut from homeschooling to various levels of inclusion within the school setting. When Nick was young, he was unable to cope with preschool settings. So, with consultation services provided, at our request, by our school district, we chose to implement an intensive at-home program for Nick for two years. Even though one early interventionist claimed we would "ruin our child's chances for future socialization," we have never found this to be the case.

We placed Nick in a full-inclusion setting with an assistant when he turned 7. We had to pressure the school district for his one-on-one instructional assistant, enduring comments such as: "We don't want to set a precedent." Eventually we convinced the district that the assistant was necessary to his success. Nick was then able to attend all regular education classes, with some curriculum and testing modifications, through the end of the eighth grade.

This year, as Nick began high school, he was scheduled to attend regular education classes only, but we soon determined that this setting was not appropriate for him. Because of adolescence and other transitions, his anxiety level rose significantly, and he had a much harder time keeping up with grade-level work. Now he spends much of his day in the resource room, with some regular-ed classes. We don't see this as a "step back" for Nick. We see it as being flexible and acknowledging what his present needs are.

An important component of the special education system is the availability

continued on page 108

continued from page 107

of a wide variety of placement options and a continuum of services. This continuum includes options from full inclusion to special class to a residential setting. Parents and professionals can work together to determine what is appropriate for each child and family. No family should ever be made to feel guilty if their choices are not in vogue or differ from the latest trend.

Federal law dictates that services be provided in the "least restrictive setting," with full inclusion the least restrictive and residential placement the most restrictive on the continuum of educational options. Parents must be prepared to exert pressure for a higher level of care (a more restrictive setting) when their child ceases to benefit from the current level of services. The real measure of the adequacy of services should be the child's ability to learn and grow within the program.

Michele and Jerry Pondolfino of New York knew their son Zachary was not developing as he should. They disagreed with their developmental pediatrician that "all children develop at different rates" and when Zachary was 8 months old, hired a county nurse to do a private evaluation. Michele relates, "The nurse validated what we suspected, that this was a very sick boy." Today, at age 7, Zachary still cannot crawl, walk or sit by himself. He has no reaching or grasping ability, he is nonverbal and both his oral and motor skills are very poor. Yet Zachary remains undiagnosed. Tests have revealed only atrophy in the frontal and temporal lobes as well as seizure activity. The Pondolfinos had finally decided that Zachary's disabilities were caused by a birth injury, until their younger son, Scottie, developed similar symptoms and a rare heart defect.

"After someone started listening, we started heading in the right direction," Michele says. "When you have a diagnosis you can then research what has worked for other individuals, as well as what to anticipate for the future. The early intervention team came out and did an evaluation, and determined that Zachary was eligible for services. By age 10 months Zachary was receiving physical and occupational therapy and even special education services."

Meanwhile, Michele gave birth to her daughter Jackie, now 5, and Scottie, now 2. Zachary eventually attended an integrated preschool program. For the first year he attended a half-day program; the following year, he went for a full day. But when Zachary turned 5, the Pondolfinos made a decision that surprised even them at first.

"We wanted a stimulating learning environment for Zachary, but knew it would need to veer from the path of conventional curriculum and teaching techniques in order for him to benefit. Obviously wheeling him up to a desk in a mainstream classroom was not going to work. We were looking for something more tailored to his capabilities and needs.

"We wanted a small classroom setting with a high teacher/student ratio, special education teachers, physical, occupational and speech therapists trained specifically to work with the most severely challenged population. Additionally, since Zach loves music, water and the outdoors, it was important for us to find a program that included these elements.

"I had heard about the Center for Discovery, a residential and educational facility in New York State, from an occupational therapist and decided to go there to look into respite services. We went for the tour thinking NO WAY would we ever consider residential placement for Zachary!" says Michele.

The family struggled with mixed feelings and held long deliberations with extended family members. The Pondolfinos made their decision to place Zachary at a residential setting with the help of their early intervention team. "Knowing that Zachary was going to receive optimal therapeutic services and creative teaching talents and have it all carried over into his after-school hours by a qualified staff of devoted caregivers gave us tremendous hope and comfort that he was indeed being given the best chance for success and highest quality of life. The staff was warm, the children were loved and well-cared-for, the facility was clean and located in a beautiful setting. I knew in my heart that this was where he needed to be."

A Medicaid waiver helped them cover expenses, and certain services were covered by the educational district. (*Note: Medicaid rules vary from state to state. Parents should research types of services that might be available to them by contacting their state's Medicaid office. Federal Medicaid Information can be accessed at: http://www.hcfa.gov/medicaid.*)

Two years later, the Pondolfinos are enthusiastic about their choice. "In the end it wasn't about us, it was about Zachary," says Michele. "We can do our best for him and we did, but they could offer something more." Many weekends, the family either visits Zachary at the Center or brings him home for a visit. Meanwhile, Scottie, who also has developed the same undiagnosed disabilities as Zachary, receives early intervention services at home, including special education, as well as physical and occupational therapy. The Pondolfinos are equally happy with this choice.

A Limit-Free Perspective

The stories above reflect only a few of the many possible choices that could be made by parents of children with disabilities. Our society is rapidly changing, and people with disabilities are gaining respect, recognition and acceptance in the larger community. Furthermore, new technologies, such as communication devices, are enabling individuals with severe disabilities to break old barriers. As parents, our continued advocacy and involvement will help further expand these possibilities.

"What brings us a lot of courage and

RESOURCES

Starred organizations also provide materials in languages other than English and/or address multicultural perspectives.

•The ARC
1010 Wayne Ave, Suite 650
Silver Spring, MD 20910
301-565-3842
http://www.thearc.org
Coordinates a network of local chapters which often offer respite care programs and other opportunities for persons with developmental disabilities, including the Sibling Support Project.

•Beach Center on Families and Disability
The University of Kansas
Haworth Hall, Room 3136
1200 Sunnyside Avenue
Lawrence, KS 66045-7534
785-864-7600
http://www.beachcenter.org
Distributes family-friendly products including manuals, booklets and videotapes. Web site offers links to statewide Parent-to-Parent organizations. Parent-to-Parent matches parents seeking information and support with other "veteran" experienced parents whose children have similar disabilities.

•The Center for Discovery
Box 840 - Benmosche Road
Harris, New York 12742
(845) 794-1400
http://www.thecenterfordiscovery.org
http://www.discoveryifi.org
A private, not-for-profit prep school that provides educational, clinical and residential programs and comprehensive on-site evaluations for children and adults with significant disabilities. The International Family Institute offers information, assistance and support to educational professionals and families of children with disabilities.

•Council for Exceptional Children (CEC)
1920 Association Dr
Reston, VA 20101-1589
888-232-7733
http://www.cec.sped.org
Provides access to an international library and database on the education of children with disabilities.

EP (Exceptional Parent)
65 East Route 4
River Edge, NJ 07661
(800) 372-7368
http://www.eparent.com
A 31-year-old integrated communications company for families, caregivers and professionals involved in the care and development of children and adults with disabilities and special healthcare needs. Provides print and Web resources and helps parents connect with experts, resources and, most importantly, other parents.

•Family Village
Waisman Center/University of Wisconsin-Madison
1500 Highland Av
Madison, WI 53705-2280
http://www.familyvillage.wisc.edu
Integrates information, resources, and communication opportunities on the Internet. Their Community Center offers many culturally diverse site listings.

MUMS: National Parent-to-Parent Network
150 Custer Court
Green Bay, WI 54301-1243
877-336-5333 (Parents only please)
920-336-5333
http://www.netnet.net/mums
MUMS connects parents of children with similar medical conditions, physical, mental or emotional disorders.

National Early Childhood Technical Assistance System (NECTAS)
Frank Porter Graham Child Development Institute,
University of North Carolina at Chapel Hill
137 East Franklin St, Ste 500
Chapel Hill, NC 27514
919-962-2001; TDD
(877) 574-3194
http://www.nectac.org
A national technical assistance consortium that supports states, jurisdictions and others in improving services and results for young children with disabilities and their families. The NECTAS Web site provides a Contact List of each state's Early Intervention Program coordinators (http://www.nectac.org/contact/contacts/asp.

•National Information Center for Children and Youth with Disabilities (NICHCY)
PO Box 1492,
Washington, DC 20013
800-695-0285;
http://www.nichcy.org
Provides free information on a wide variety of disabilities and helps to identify educational programs and services.

Office of Special Education Programs (OSEP)
U.S. Department of Education
400 Maryland Ave, SW
Washington, DC 20202
202-205-5507
http://www.ed.gov/offices/OSERS/OSEP
Administers the Individuals With Disabilities Education Act (IDEA).

•Parent Advocacy Coalition for Educational Rights Center (PACER)
8161 Normandale Blvd
Minneapolis, MN 55437
952-838-9000
http://www.pacer.org
PACER Center provides assistance to individual families, workshops, and materials for parents and professionals, and leadership in securing a free and appropriate public education for all children. PACER's Technical Assistance Alliance for Parent Centers project (Web site: http://www.taalliance.org/) coordinates Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) which are available in each state to provide training and information to professionals and parents of infants, toddlers, children, and youth with disabilities.

Wrightslaw
Harbor House Law Press, Inc.
P.O. Box 480
Hartfield, VA 23071
(877) 529-4332
http://www.wrightslaw.com
A free Web site offering extensive legal information about one's rights and protections regarding special education.

hope is not giving up or setting limits on our child. One does not know the potential of any human. With each skill learned, the bar gets moved up a notch for the whole family. With our son, any progress is great progress," notes Purnima Hernandez.

We will always see our children from the unique perspective of a parent, and this view generates a passion like no other. Together we can use that passion to encourage change, initiate reforms and create new opportunities to enhance our lives and the lives of our children. EP

Elizabeth King Gerlach is the mother of a 16-year-old son with autism and a 14-year-old son with attention deficit disorder. She is a writer/editor and the author of two award-winning books, Autism Treatment Guide and Just This Side of Normal: Glimpses into Life with Autism (both published by Future Horizons). She has also spoken nationwide on autism and parental advocacy and involvement.

WWW.EPLIBRARY.COM

EP Exceptional Parent LIBRARY

THE SPECIAL NEEDS BOOKSTORE

PARENTING

The Angry Child
Regaining Control When Your Child is Out of Control
Tim Murphy, Ph.D.

Anger can be a normal response to frustration or disappointment, but for some children it is an ingrained behavior that caused them and those around them needless misery. This book provides both the roots and the solutions for uncontrollable anger in children. Learn the 10 characteristics of the angry child; Four stages of anger and how to cope; the 5 C's of successful parenting and much more.

RH676XPA $24.00

Father Need NEW!
Why Father Care Is as Essential as Mother Care for Your Child
Kyle D. Pruett, M.D.

An easy to follow handbook which offers in depth advice for parenting children of all age groups from infancy through adolescence and adulthood. Learn not only why a father needs to take an active role in raising children, but also how to do so effectively.

RH7371PA 13.95

Special Kids Need Special Parents
A Resource for Parents of Children with Special Needs
Judith Loseff Lavin NEW!

Parents of children with special needs face unique emotional and practical challenges every day. These issues are seldom fully addressed by the medical community—an parents' most compelling questions remain unanswered. The author draws upon interviews with health care professionals, nationally recognized authorities and families of special need children to give readers the advice, encouragement and comfort they crave.

GP6622PA $13.95

The Parent to Parent Handbook
Connecting Families of Children with Special Needs
Betsy Santelli, Florene Steward Poyadue, Jane Leora Young

As a parent you have lots of questions, If you child has a disability you probably have even more. One of the best ways to find answers to your questions is through "Parent to Parent Programs". Written by two mothers that have been there this book will explain how these valuable programs work and how they can give you the help you need.

PB4979GN $29.95

HOME SCHOOLING

Homeschoolers' Success Stories
Linda Dobson

15 adults and 12 young people share the impact that homeschooling has made on their lives. This is not a how to book but rather a how it was done book.

PR2557HS $16.95

The Challenge of Osteoporosis For People With Disabilities
A look at risk factors and prevention
Ian Smith, M.D.

Many of the 54 million Americans with disabilities-including those with cerebral palsy, muscular dystrophy, multiple sclerosis, spina bifida and other physical disabilities face special health challenges. Osteoporosis, or thinning and weakening of the bones, is one of the most critical. This 15 minute, full-color, broadcast quality video comprehensively explores the impact of osteoporosis for individuals with physical disabilities. Developed as an informational and training tool for a wide audience, including people with disabilities and their caregivers as well as the general public.

UCP010S Reg: $149.00 Sale Price: $99.00

Homeschool Your Child For Free
Laura Maery Gold and Joan M. Zielinski

An invaluable guide to all the best in free educational material - from reading-readiness activities for preschoolers to science projects for teens-categorizes, reviews, and rates more that 1200 of the most useful educational resources on the Internet and beyond. Includes Legal guidelines and compliance requirements; complete curriculum plans for a comprehensive education, from preschool through high school; On line lesson plans arranged by subject and much more.

PR5130HS $18.95

FOR YOUNG PEOPLE

Ben King Of The River
David Gifaldi with illustrations by Layne Johnson

The touching story of Ben, a young child with a developmental disability, and his brother who encounter some different and exciting situations and people on a family camping trip.

AWG354YP $14.95

Baby on the Way
William Sears, MD, Martha Sears, RN, and Christie Watts Kelly with illustrations by Renee Andriani

When a family is expecting a new baby there are many changes that take place. This warm insightful book helps children and their parents joyously and lovingly prepare for the newest member of the family. NEW!

TW7671YP $12.95

What Baby Needs
William Sears, MD, Martha Sears, RN, and Christie Watts Kelly with illustrations by Renee Andriani

When a family brings a new baby home there are many changes. This children's book clearly explains baby's needs while emphasizing how siblings can be helpers to both baby and parents, while forging their own relationships with "the baby".

TW8287YP NEW! $12.95

EPILEPSY

The Ketongenic Diet
A Treatment for Epilepsy
John M. Freeman, MD, Jennifer B. Freeman, Millicent T. Kelly, RD, LD

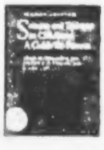
Devoted exclusively to explaining a unique doctor approved approach to minimizing seizures, this book is a must have for all families affected by epilepsy and seizures. The diet presented within is high in fat and low in carbohydrates and protein, helping to control seizures and allow children to lead normal seizure and drug free lives.

DE9390EP $24.95

Your Child and Epilepsy
Robert J. Gumnit, M.D.

This book is designed to help both patients and healthcare professionals to understand all aspects of diagnosis, and of pharmacological and surgical management. It will help parents and older children with epilepsy to participate more knowledgeably with their health care providers

DE7760EP $24.95



Seizures and Epilepsy in Childhood
A Guide for Parents
John M. Freeman, M.D.

This Second Edition in addition to providing up to date information about new diagnostic techniques, drugs, diet and surgical treatments; includes a new chapter addressing the special needs children with epilepsy have regarding routine health care.

JH4989EP $17.95

ASPERGER SYNDROME

Blue Bottle Mystery
Kathy Hoopmann

A warm, funfilled fantasy story that enables children with Asperger syndrome to read about their disability in a non threatening way that promotes the best in them.

TT978S NEW! $11.95

Asperger Syndrome, the Universe, and Everything
Kenneth Hall

The author was diagnosed with Asperger Syndrome at age eight, and now he describes some of the inner experiences and perceptions a child with autism has from a unique perspective that only one who has been through it can truly explain.

TF8300AS $11.95

Of Mice and Aliens
An Asperger Adventure
Kathy Hoopmann

Ben, recently diagnosed with Asperger Syndrome, and his friend Andy uncover an alien spaceship that crash landed in their backyard. With Ben trying to cope with his disorder, and the alien trying to cope with life on earth, adventure ensues.

TF0071AS $11.95

Coming Soon!!
EPLibrary Book Club
Learn more by sending us an email at
eplibrary@aol.com
with UPDATE in the subject.

EP LIBRARY • (800) 535-1910 • EPLIBRARY@AOL.COM

PHYSICAL DISABILITY

MUSCULAR DYSTROPHY IN CHILDREN
A Guide for Families
IRWIN M. SIEGEL, MD

Written for children with muscular dystrophy, their parents, families, teachers, and friends, this book will help all involved in understanding the significance of the signs and symptoms, the treatment options probable outcome, and current therapy choices available.

DE9330PD **$19.95**

YES YOU CAN !!!
Go Beyond Physical Adversity and Live Life to its Fullest
JANIS DEITZ, PHD

Embracing the premise that life should be lived to its fullest, disability or not, this book presents ways for anyone to weather challenges, illnesses, or disabilities. An energetic and zest-filled read, the book will leave you with a "can-do" attitude

DE9483PD **$15.95**

BEHAVIOR

THE ANTI-BULLYING HANDBOOK
KEITH SULLIVAN

Written for Parents, teachers, administrators, counselors, therapists this resource can help us to understand what bullying is and how to arrest it or to prevent it. Part I gives a clear overview of what we understand about bullying and Part II provides information on how to deal with with bullying.

OU3884BE **$19.95**

RAISING CHILDREN WHO REFUSE TO BE RAISED
DAVE ZIEGLER, PH.D.

This book is for both parents and professionals who are involved with the care of children who have severe emotional or behavioral disturbances as the result of abuse or neglect. The three major sections cover: Emotional disturbances, Where it all Begins; Behavioral Disturbances: There is More than Meets the Eye; and lastly Advanced parenting Skills and Challenges. The 12 chapters contain detailed discussions of emotional or behavioral disorders, their causes and possibilities for treatment.

AC8727BH **$19.99**

AUTISM

AUTISM AND THE NEW LAW
Resources for Treatment, Hope for Cure
NARRATED BY: ANTHONY EDWARDS

This 30-minute video is designed to help parents, educators, and health care professionals better understand Autism or similar diagnosis such as PDD and Asperger Syndrome. Learn about the components of The Advancement of Pediatric Autism Research Act and how it affects the lives of you, your child, and your family.

EV6882AT **$49.95**

FRAGILE SUCCESS
Ten Autistic Children, Childhood to Adulthood
VIRGINIA WALKER SPERRY, M.A.

In this book you will get a view of autism in all its variations as the author, a former teacher, traces the lives of her students over 30 years These true case histories provide exceptional insight into the mystery and diversity of autism.

PB4587AT **$24.95**

RAISING A CHILD WITH AUTISM
A Guide to Applied Behavior Analysis for Parents
SHIRA RICHMAN

Applied Behavior Analysis (ABA) is increasingly recognized as a highly effective way of helping children with autistic spectrum disorders. The author explains how parents can adapt the practical techniques used in ABA for use at home, providing tips and advice for families and parents.

TF9106AT **$19.95**

AUTISM THROUGH THE LIFESPAN
The Eden Model
DAVID L. HOLMES. ED.D.

A unique and detailed look at a successful approach to treating and caring for children with autism. Parents, teachers, and treatment professionals will find this book to be informative and insightful reading.

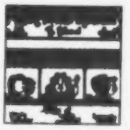
WB1764AT **$21.95**

TOURETTE SYNDROME

TOURETTE SYNDROME: FINDING ANSWERS AND GETTING HELP ***NEW!***
MITZIE WALTZ

Tourette's syndrome is a neurological disorder usually diagnosed in childhood. It is characterized by tics; physical jerks and involuntary vocalizations. Some people with Tourette's also have other brain-based disorders, particularly ADHD or OCD. This book is designed to help you: Secure accurate and complete diagnosis; Live with Tourette's in the family; Understand medical interventions; Obtain appropriate medical care from an existing health plan; Find resources and much more.

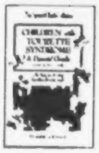
DA0076TS **$24.95**



TAKING TOURETTE SYNDROME TO SCHOOL ***NEW!***
TIRA KRUEGER WITH ILLUSTRATIONS BY TOM DINEEN

This excellent children's story about a girl with Tourette Syndrome is essential for any family that wishes to understand what the disorder is, where it comes from, and what impact it has on the child's life.

JB3124TS **$11.95**



CHILDREN WITH TOURETTE SYNDROME
A Parents' Guide
Edited by T. Haerle

Written by a team of professionals and parents, this book covers medical, educational, legal, family life, daily care, and emotional issues.

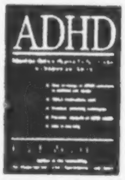
WB01E0D **$14.95**

ATTENTION DEFICIT

DISTANT DRUMS, DIFFERENT DRUMMERS
A guide for young people with ADHD
BARBARA D. INGERSOLL, PH. D.

A view that offers children and adolescents struggling with ADHD the opportunity to see themselves in a positive light due to their penchant for novelty and exploration and boundless energy.

CP100AD **$15.95**



ADHD
Attention Deficit Hyperactivity Disorder in Children, Adolescents, and Adults
PAUL H. WENDER, M.D.

This book is filled with extensive case histories of children and adolescents with ADHD. It contains valuable information on where to seek help, as well as on the kinds of diagnostic tests currently available. This is a must have for parents of children with ADHD.

OU3497AD **$10.95**

TEACHING TEENS WITH ADD AND ADHD ***NEW!***
A Quick Reference Guide for Teachers and Parents
CHRIS A. ZEIGLER DENDY, M.S.

Recognizing the pivotal role teachers play in the long term success of their students, this book provides information via 75 concise summaries on key issues related to attention deficit disorder. Beyond the thorough review of the basics, this guide also illustrates how the characteristics of the disorder can affect academic performance while presenting strategies interventions and tips to make teacher's jobs easier.

WK7295AD **$18.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: **EP**, Dept. EP0602, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call **800•535•1910**

QTY	ITEM#	UNIT PRICE	TOTAL
		Sub-Total	
		NJ Residents 6% Sales Tax	
		Shipping	
		TOTAL	

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

These prices are subject to change without notice.

Name ____________________
Address ____________________
City ____________________ State __________ Zip __________
Telephone ____________________ E-Mail ____________________
I have enclosed my check payable to EXCEPTIONAL PARENT or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover
Account Number: ____-____-____-____ Exp. Date ____/____
Signature ____________________

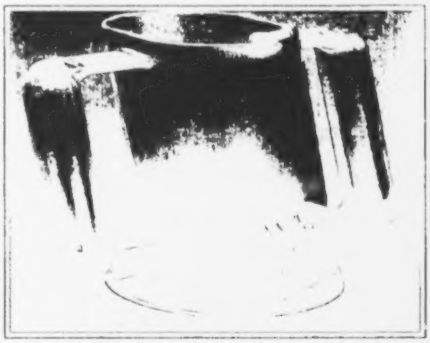
Circle #200

new products

MUSICAL FINGERPAINT

Musical Fingerpaint is a portable easel that can stimulate the sense of touch and provide eye-hand coordination practice for children 9 months and up. Fingerpainting is created when the child touchs the easel's special surface with fingers or one of the four included drawing tools. One of three songs plays when the surface is touched. The music and painting stop when touch is removed. The songs can also be activated by pushing a musical note button. The surface is easily cleaned by sliding the attached roller bar across it. The toy requires three "AA" batteries.

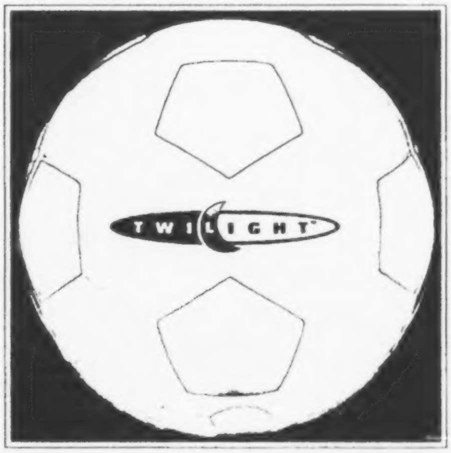
Fisher-Price, Inc.
636 Girard Ave., E. Aurora, NY 14052
800-432-5437, 716-687-3000, 716-687-3494 fax
E-mail: fisher-pricestore@pleasantco.com;
Web site: http://www.fisher-price.com



ABLEWARE® HANDY CUP

The ABLEWARE® Handy Cup is a transparent cup with an extra wide base. The two handles provide a secure grip and stability. The angled design makes it possible to drink with little or no neck movement while allowing space for nose and eyeglasses. The eight-ounce ABLEWARE® Handy Cup is also dishwasher safe.

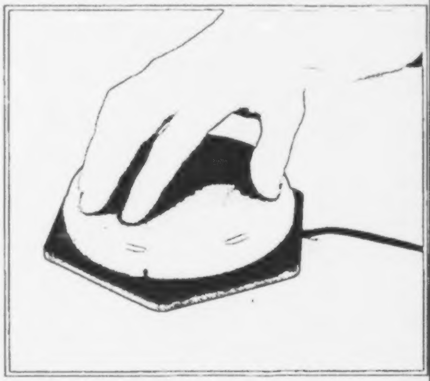
Maddak Inc., 6 Industrial Road. Pequannock, NJ 07440; 973-628-7600, 800-443-4926;
E-mail: custservice@maddak.com; Web site: http://www.maddak.com



TWILIGHT™ LIGHTED SOCCER BALL

The Twilight™ Lighted Soccer Ball utilizes a patented Hyperlight™ LED lighting system, which creates a bright orange glow. This soccer ball is constructed from synthetic rubber compound for lasting durability. With an automatic shut-off feature, the soccer ball turns off after five minutes of inactivity. The Twilight Lighted Soccer Ball is available in three sizes: Official regulation, intermediate and youth sizes.

Huffy Sports Company.
N53 W24700 S Corporate Circle, Sussex,
WI 53089; 800-558-5234;
E-mail: service@huffynet.com;
Web site: http://www.huffysports.com



JOGGLE

The JOGGLE is a variable pressure switch with fifteen increments of pressure adjustment. Simply rotate the top to increase or decrease the force required for activation. The JOGGLE is available in red, green, yellow and blue.

Tash Inc., 3512 Mayland Court, Richmond VA 23233; 800-463-5685, 804-747-5020, 804-747-5224; E-mail: tashinc@aol.com;
Web Site: http://www.tashinc.com

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

Easy Reader
The uniquely liberating Reading Machine isolates a line of text and allows readers with visual-perceptual and fine motor challenges to scroll through the text of **Real Books**.
Call 914-631-1317.

Circle #1

Lets your child communicate using only his eyes!
Eye controlled speech synthesis, environmental controls and PC/computer access
Now It's Portable !
800-393-4293 www.eyegaze.com
LC Technologies, Inc., Fairfax, Virginia

Circle #2

Diaper Doublers™

Diaper Doublers inserts that make cloth or disposable diapers more efficient, pulling moisture away from a child's tender skin.

- Trim & Comfortable
- Overnight Protection
- Absorbency without Bulk
- Latex-Free for Sensitive Skin

www.DiaperDoubler.com
1-800-335-4434
Toll-Free Phone Orders
"The Drier Way to Diaper"™

Circle #3

freedom
what is your definition?
call us today!

1.800.661.9915
www.freedomconcepts.com

Circle #4

tfh Lots of fun products
@ www.tfhusa.com
& 800 467 6222
Get ready for the Beach

Save $50
Wheel Chair Friendly

TFH Sand and Water Tray
2 deep Sections,
Adjustable Legs,
Draining Tap, Casters.
$349

Circle #5

INTRODUCING
the Invacare® Top End® Terminator® Jr.
for kids who are going places!

A super stable, adjustable chair that grows— and that kids can move all by themselves.
INVACARE
Yes, you can.®
2001 Invacare Corporation. Invacare, Terminator, Top End and Yes, you can are trademarks of Invacare Corporation.

Circle #6

Natural Access™
Expand your horizons with the Landeez All-Terrain Wheelchair!

Rolls easily over sand, snow, gravel, and uneven terrain, so you can enjoy the outdoors

For more info 800-411-7789 or visit
www.landeez.com

Circle #7

MARKETPLACE

ACCESSIBLE TRAVEL

Disney Area Villa rentals
4 miles from Disney World. 3/2 (sleeps 8) Accessible Resort Villa. All your Special Needs, Scooters, Oxygen, Cruises & Dialysis Program by www.medicaltravel.org Call 1-800-778-7953.

ATTORNEY

Attorney Richard Gottesman
(800)295-1107
gottesman@law.com
Cerebral Palsy, Brachial Plexus/Erb's Palsy and Childbirth Injuries

BEACH WHEELCHAIR

Affordable Independence in the Great Outdoors!

The Features Make All the Difference!

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure

BEACH SWIMMING POOL

TIRALO™
Floating Beach Chair

Call now: (360) 796-3197

www.oasisllc.com

DIAPERS

DIAPERAPS®
Since 1984
Youth Swim Diapers
1-800-477-3424
www.diaperaps.com

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

Special-Needs Collection

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

EQUIPMENT DEALERS

American
Discount Medical
Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider.
Resource information:
www.medmarket.com
e-mail: info@archhp.com

Ask about our Youth Brief sample pack. Only $5.99!

HDIS **FREE CATALOG**

Call Today!
1-800-2MY-HOME™
(1-800-269-4663)

UNIQUE GIFTS

It's always the right time to appreciate those educators and healthcare professionals who work with our kids!
At **www.4medspeak.com** you will find unique gifts for speech pathologists, special ed teachers, therapists, home caregivers, pediatricians, etc.

MEDICALLY SPEAKING
www.4medspeak.com

FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg.
PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

MONITORING SYSTEM

Care Electronics Inc.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price. Call for FREE CATALOG

RESOURCES

EXCEPTIONAL PARENT

Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores All Across America. Every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books. $4.95 Cover Price.

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/ handling). To order, call 1-800-535-1910.

SEATING & POSITIONING

Designed With Children In Mind
Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Leckey products feature lighter mobile bases, more adjustable components, peer level positioning, child friendly positioning straps and playful colors.

- Freestander
- Totstander
- Easy Seat
- Advance Bath Chair
- Toilet/Shower Chair
- Basic Bath Support
- Pronestander

Call Sammons Preston today at 1-800-323-5547 for a complete Leckey® brochure.

MARKETPLACE

SWITCHES

BUBBLES™ SWITCHES — for those who have difficulty using ordinary switches. Touch-sensitive, or it can be set so the hand only needs to pass near the switch! Convenient dome shape.

MINIMAL MOTION™ SPLINT SWITCH KITS — touch-sensitive switch pads to mount directly on hand splints.

EQUAL ACCESS COMPUTER TECHNOLOGY, INC. 978-466-9191
222 Grant Way, Lancaster, MA 01523
Email: eact@world.std.com

SWINGS

Portable Swing Stand

Therapy Swings

Safe, strong comforting & affordable for all your swinging and spinning needs

For more information contact
Take-A-Swing LLC
602-451-5544 • www.takeaswing.com

TOYS & HOBBIES

TFH (USA) LTD
4537 6B Sonia RD.
Gibsonia, PA 15044
(800) 467-6222
www.tfhusa.com
e-mail: info@tfhusa.com
Fun products for retreat on and education of special needs children. Request a free catalog.

VAN CONVERSION DEALERS

MASSACHUSETTS

MOTION AUTOMOTIVE SPECIALTY
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—
Day, Week or Month.

TO ADVERTISE IN MARKETPLACE CONTACT: **Barbara Nastro**

TEL: (908) 534-6366 • FAX: (908) 534-6941

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

Send us your child's photo!

EP is always looking for submissions for our monthly *Familiar Faces* column.

It may just end up on our cover!

Send to: EP, 65 East Route 4, River Edge, NJ 07661

Camphill Special School

Children's Village

A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- Pennsylvania Approved Private School
- Waldorf Curriculum (Member of AWSNA)
- Both Day & Residential Programs Available

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236

www.BeaverRun.org

Circle #24 or visit www.eparent.com/adinfo

The Miracle of Life

by Lee Lipschutz

Lee Lipschutz shortly after becoming a big brother and his little sisters.

What is a miracle? I define it as a rare event that—despite any adversity—has occurred, for reasons beyond human control. The definition of a miracle can also include my twin sisters, Robyn and Ellen.

I remember walking up the steps to my house on September 18, 1986. I was 5 years old then and a typical innocent boy. As I went into the house, a feeling of solitude ran through my body. Where was my mother? There was a fading silence as the pounding of my heart became louder and faster. Slowly, as I approached the kitchen, my eyes grew wide as I found my grandmother standing there, purse in hand.

She grabbed my hand and we dashed to the car. On the way she gave me the news of which I understood just three words: Mom in hospital. At that age, I only knew that the hospital meant something bad. That was the longest car ride I had ever experienced. I felt overwhelmed when we arrived at the hospital. It was bustling with activity.

After an elevator ride and a short walk that felt like an odyssey, we arrived at my mother's room. I wondered, "Is she all right? What will I see?" I twisted the knob and slowly pushed the door open. Straight ahead, in the room, was my mother dressed in a nightgown and my father sitting alongside her. Everything seemed okay. I felt her joy as she watched me come toward her.

I really couldn't comprehend all she said, but I did understand a couple of things: I was the brother of twin sisters; they were very small and sick; and I couldn't see them yet. She also said that the doctors were not sure if they were ever going to walk, talk or eat food. A chill ran through my body. She told me that they weighed one pound eleven ounces and one pound eight ounces. I knew then that as I grew older, I would progressively understand the hardships that my sisters have endured.

Now, I can see how remarkable and miraculous their battle for survival has been. My sisters have been through eye surgery, heart surgery, brain surgery and many more life-threatening, painful surgeries. They've overcome many adversities. They have taught me that the impossible can and does happen. I admire both of them for their hard-fought battles that continue to this day. They also make me aware of how easy most of us have it. Now, I can see the other side of life with its hardships, struggles and pain met by human beings everyday.

Now ask yourself, how do you define a miracle? EP

MOM'S TURN

Beverly Roach, mother of Lee, Robyn and Ellen, writes:

Lee (now 20) wrote this as his college entrance essay. His sisters, Robyn and Ellen, were born 15 weeks early. The girls are now 15 years old and are doing well. (Robyn is in high school and also attends vocational training. Ellen attends her county's special education program.)

Many people have read Lee's essay and were touched by its sensitivity. Lee now attends Stony Brook University on a baseball scholarship.

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number, and e-mail address! ***Now on the Web!*** We now include **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

PEACE OF MIND

When it comes to your child, you don't compromise. Safety is indispensable. You demand quality. Reliability. Functionality.

The Lisa pediatric postural mobility system from Otto Bock gives you all this while maintaining its playful good looks. So go ahead. Take it "off sidewalk". Recline the back rest up to 130°. Accessorize to your heart's content. And enjoy how easily it folds and how little it weighs. You and your family deserve it.

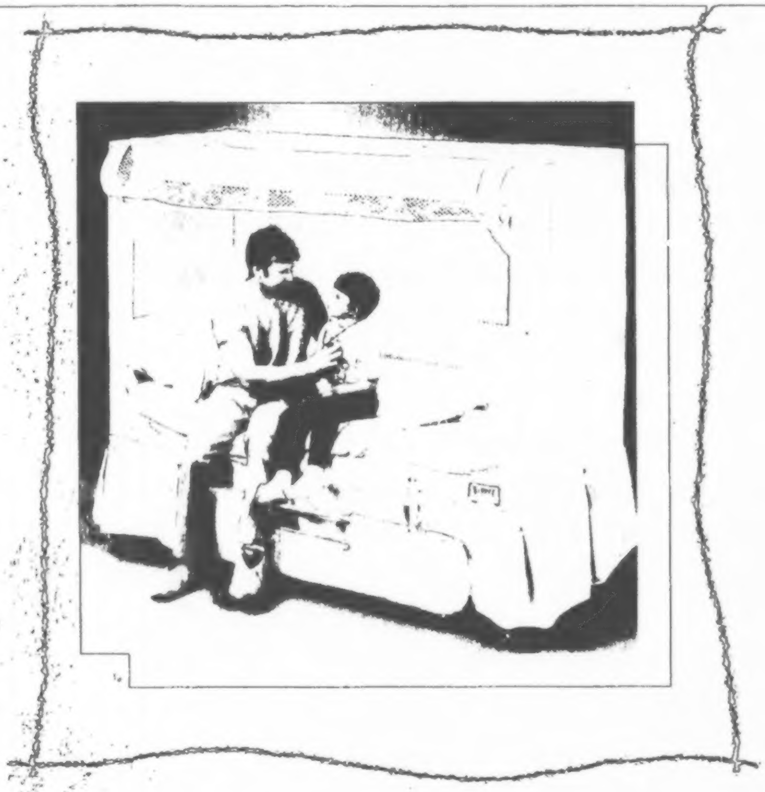
For more information, visit www.ottobockus.com, or call 1-800-328-4058 to find a dealer near you.

Otto Bock
HEALTH CARE
www.ottobockus.com

Circle #55 or visit www.eparent.com/adinfo

A Better Bedtime Story

The Vail Enclosed Bed



Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for your child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt. Plus, we provide assistance in obtaining insurance approval.

Available from home health-care products dealers, or direct from the manufacturer.

For a FREE catalog, call: 1-800-235-VAIL

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard

Ask about Our Decorator Accessories.

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

Sheri Wittmer
Sandusky, Ohio

Vail Meadows Therapeutic Riding Center

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for challenged riders.

Circle #69 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community

PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent

JULY 2002
$4.95

MARINE SPECIAL FAMILIES HAVE SPECIAL PROGRAMS & LEADER

Summer Independence for Teens

Baseball's Field of Miracles

www.eparent.com

The Center for DISCOVERY

sigma-tau PHARMACEUTICALS, INC.

Cyberonics

CHILD NEUROLOGY SOCIETY

******************************5-DIGIT 22201
22201AQU111CUD0 ZNI02
ACQUISITIONS
ERIC CLEARINGHOUSE R= 4876
COUNCIL FOR EXCEPT S163 PS
1110 N GLEBE RD STE 300
ARLINGTON VA 22201-4795

BEST COPY AVAILABLE

Imagine...

if all of your other
choices could be this simple

MOTOR COMPANY INC LIBERTY

Introducing a
zero
maintenance
conversion van with wheelchair acce

Starting Under
$20,000 US
(Including vehicle and modification)

- 1996-2002 Windstar Models Available (All vans come with brand new conversions)
- Professionally trained staff ready to help you
- The rear-entry design provides for the safest and most reliable wheelchair accessible minivan on the market.
- The Liberty Motor Co modified Ford Windstar looks and drives like a standard minivan, offering a quiet, comfortable ride.
- Money Back Guarantee

Circle #49 or visit www.eparent.com/adinfo

1 (888) 578-8886 www.libertymotorco.com

ERIC Clearinghouse on Disabilities and Gifted Education
Suite 300
1110 North Glebe Road
Arlington, VA 22201-5704

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

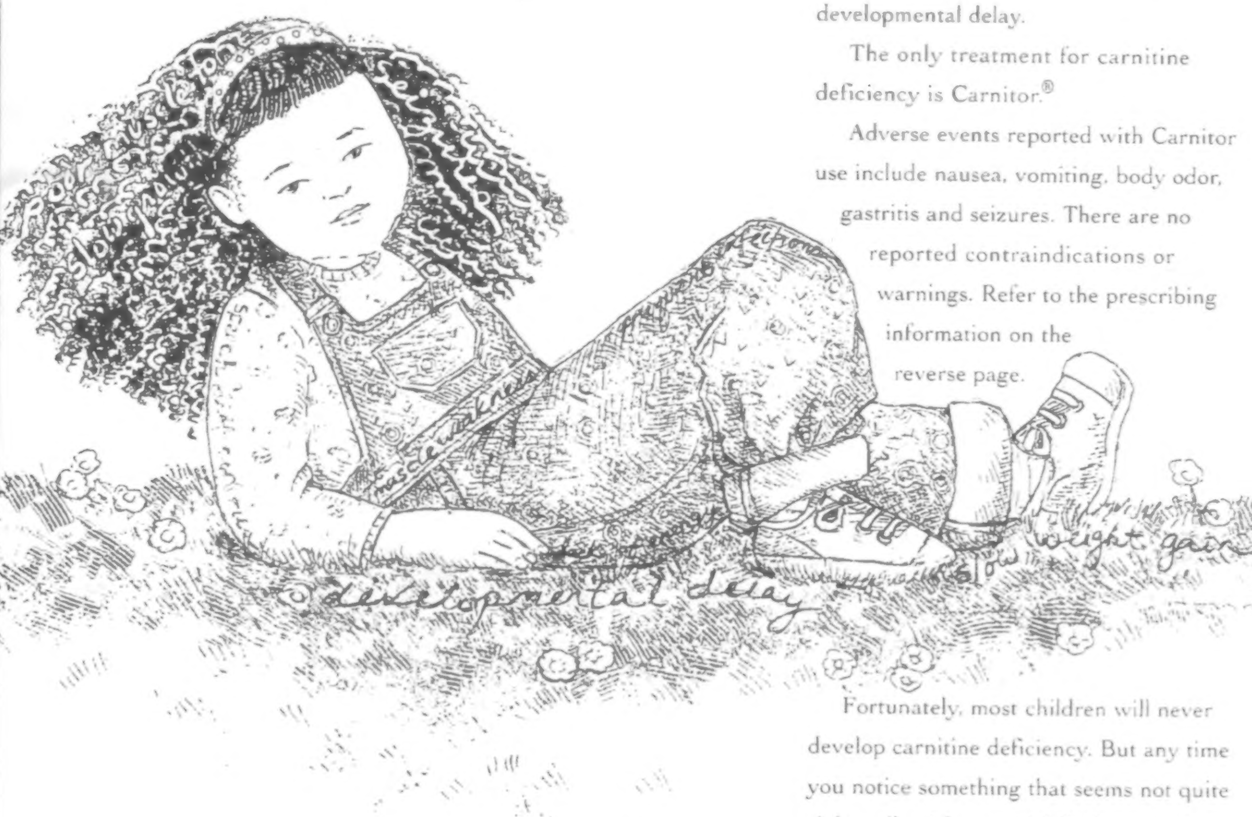
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

contents

JULY 2002 • VOLUME 32, ISSUE 7

Teen & Young Adults

32 Independence in Teens During Summer Break: Techniques to Reinforce Life Skills at Home
By Carolyn O. Cantu, MS, OTR
Simple ways to keep teens practicing skills taught in during the school year.

36 Getting Youth Up to PAR: Using Participatory Action Research to Increase Self-Determination Skills
By Jessie Sandoval, Tanis Bryan, PhD, and Karen Burstein, PhD

42 Miracle League Playing Fields Make Dreams Come True
By Maria Tortoreto
Baseball league for children with disabilities gives everyone a chance to play.

48 Camp Adventure
By Bridget Lyne
Arizona camp gives children with disabilities opportunities for outdoor summer fun.

FEATURES

13 Meet the Joneses
The Corps' First Family discuss their lives, the impact of having a child with special needs and their Marines.

52 Hyperbaric Oxygen Therapy (HBOT)
An introduction to the questionable therapy for cerebral palsy.

65 Sports Corner NDSA
By Debbie Akins
A New Sport for those who love Bocce.

62 Conquering the Jargon Jungle: Technology Terms a Parent Needs to Know
By Sheryl Burgstahler, PhD
What some of those technical words mean and how to advocate for them.

SPECIAL REPORT:

78 Sports Injury Prevention and Trauma
By Manfred Friedman, DDS
How to care for he most common injuries sustained during sport activity: Chipped, broken and avulsed teeth.

SPECIAL REPORT:

87 Informing, Empowering and Keeping Parents Involved: A Four Part Series
by Lauren Agoratus
Part 2: The Decision and the Battle

COVER: General James L. Jones, Commandant of the Marine Corps and his wife, Diane, are shown with their daughter, Jennifer, 27, who was diagnosed with Fragile X Syndrome. As parents and Marine Corps leaders, they have been supporting heightened efforts to help special needs service families.

EP
Exceptional Parent

contents

DEPARTMENTS

8 **Editor's Desk**

10 **Search and Respond**

23 **Organizational Spotlight**
The National Fragile X Foundation

58 **What's Happening**
Appeals Court Allows Patients to Sue States
New Publication on Parentally Placed Students
Jewelry Promotes Equality
NDSS Launches Web site for Teens

60 **Further Reading**
By Megan Henninger
A quick look at titles that offer information on transitioning from teen to adult life.

68 **Ask the Doctor**
By Jeanne A. Marron, PhD
Positive Reinforcement Programs for Your Child with Attention Deficit/Hyperactivity Disorder (AD/HD)

72 **Research Reflections**
By Dr. Jan Blacher
Tourette's Syndrome and Associated Disorders

92 **EP Library**

94 **Familiar Faces**

96 **New Products**

100 **Children's Page**
Danny
by Rich Psillos

My Brother
By Jessica Psillos

EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTH CARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

EXCEPTIONAL PARENT (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy Ed Corp., dba *EXCEPTIONAL PARENT Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy Ed Corp. *EXCEPTIONAL PARENT*® is a registered trademark of the Psy Ed Corp. **Postmaster:** Please send address changes to: *EXCEPTIONAL PARENT*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *EXCEPTIONAL PARENT*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *EXCEPTIONAL PARENT*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #4006-0754. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

EXCEPTIONAL PARENT neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR IN CHIEF:
While hyperbaric oxygen is effective therapy in certain conditions it is currently considered an alternative therapy for CP and other "brain insult" conditions. Readers are advised to discuss the advisability of HBOT with their primary or specialty healthcare providers as well as to study the current literature.

—*Rick Rader, MD*

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

MITCHELL F. BRIN, MD, Vice President, Botox, Allergan, Irvine, CA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician in Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics, Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof. Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

HARILYN ROUSSO, ACSW, Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

THERESA VARNET, MSW, JD, Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #71 or visit www.eparent.com/adinfo

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Serving Adults having MR/DD

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #19 or visit www.eparent.com/adinfo

EP

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

Editor-in-Chief	Rick Rader, MD
Consulting Managing Editor	Donald P. Mazzella
Senior Editor	Kristen George, MAT
Medical Editor	Fern R. Potvin
Assistant Editor	Megan Henniger
Editorial Intern	Maria Tortoreto

President, CEO & Publisher	Joseph M. Valenzano, Jr.
VP Business Development & Internet Projects	Vanessa B. Ira
VP Organization Relations & Consulting Editor	Bridget M. Lyne
Chief Financial Officer	Dolores A. Kinley
Ad Traffic Manager	Kendra Kelly
Sales Coordinator	Doris DeFina
Receptionist/Public Relations Coordinator	Robyn Sager
Art Direction, Design	Publishers Design Group, Inc. ✉annpdg@aol.com
Production Manager	Michael Longobardi
EP Library	Ron Richards (800) 535-1910 ✉eplibrary@aol.com
Webmaster	Ken Fleischer, Dynamic Media Works ✉webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Jared Adams - South East
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉jadams@eparent.com
DE, MD, DC, WV, VA, NC, SC, GA, FL, KY, TN, AL, MS, LA, AR, MO

Larry Battistello
Marketing Plus
3155 East Ramon, Unit #203
Palm Springs, CA 92264
✉ seemelads@aol.com
TERRITORY: WA, OR, ID, NV, CA, UT, CO, AZ, NM

Vanessa B. Ira
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 ext. 209
✉ vira@eparent.com
CANADA

Annabelle & Gabe Jacobson - Central
(847) 256-6850
✉ bellyon@megsinet.net
MI, WI, IA, IL, IN

Bill Joubert
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ bjoubert@superlink.net
MT, ND, MN, SD, WY, NE, KS, OK, TX

Barbara Nastro
4 Glenmont Road
Whitehouse Station, NJ 08889
✉ nastro@blast.net
NJ, PA, SCHOOLS, CAMPS & RESIDENCES, MARKETPLACE

Matt Valenzano
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 x211
✉mattvalenzano@eparent.com
ME, VT, NH, MA, RI, CT, NY

Color Separation/Film Preparation
AGT7 Carlstadt, NJ 07072

List Rentals
GRS
Mktg Services Inc.
187 Ballardvale Street
Wilmington, MA 01887
Attention: Mark Hammar
978-661-8126
mhammar@mktgservices.com

Publishing & Editorial Office
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

Subscriber Service:
Exceptional Parent
P.O. Box 2078, Marion, OH 43306-2178.

Customer Service/New Orders:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

Exceptional Parent magazine was founded in 1971 by Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 82

More Smiles

New & Improved

Safari Tilt

When you talk...
we listen

The new and improved Safari chair is something to smile about.

- New instructional video*
- Improved fold
- New style heel loops
- Optional recline, 5 - 45 degrees
- Easy to tilt
- Crash tested

*Ask for free introductory video

Convaid

Circle #29 or visit www.eparent.com/adinfo

O Box 4209, Palos Verdes, CA 90274 USA o Tel 1-888-CONVAID (266-8243) / FAX 310-618-8811 www.convaid.com

editor's desk

EVERYTHING'S RELATIVE TO EXCEPTIONAL PARENTS

I admire Einstein. Okay, I admit it; I'm an Einstein groupie. Some mornings I even have his hair. I have Einstein calendars, coffee mugs, posters, neckties, T-shirts, biographies and even a life size soft sculpture of him sitting in my office. . I have everything Einsteinium except his problem solving skills.

I've liked the guy ever since I was growing up. It's easy to like Einstein despite the fact that he was so radical a thinker that his brilliance is difficult to grasp. In addition to his theories that changed the way we look at the universe (not that I'm sure that we can actually "look" at the universe) he was dedicated to campaigning for world peace. And then there were those baggy pants and rumpled sweaters. As a guy who's lucky enough to be able to wear jeans and denim shirts to work I appreciate that as an aid to thinking about the big issues. Baggy sweaters are great to sweat out the details about the space-time continuum, the photoelectric effect and quantum theory. At my office we sweat out the details about self-determination, teaching direct support professionals the nuances of non-verbal pain expression, controlling seizures and figuring out how best to integrate dignity into incontinence. In terms of magnitude I'd match our daily concerns with his any day, Relatively speaking.

Probably the neatest thing about Einstein wasn't even true. Growing up, at least in Brooklyn, where you would periodically be reminded of your shallow skill sets in the classroom, on the ball field and especially in the movies trying to maneuver your right arm from her shoulder, you needed an identifiable icon. Someone who failed at something and moved beyond it. Some guys referenced Babe Ruth, but for me it was Albert Einstein. When I heard that he failed algebra I knew we had a connection. When I heard at age nine he spoke hesitantly I knew I had arrived. I didn't let the facts dissuade me. In reality he never failed math but he did fail the entrance exam to the Polytechnic Institute of Zurich; that was enough for me. I had to walk home with my share of papers that had "have your mother call me" scribbled in red on part of the paper. I would periodically reflect on the words from his "gymnasium" (high school) teacher in Munich, "Your mere presence here undermines the class's respect for me."

A New York Times writer captured the essence of this "balance" of nature. "Albert Einstein, so the story goes, was playing in a chamber group one afternoon, and it wasn't going well. Finally, after several false starts, the conductor turned to him and asked: "Einstein! Can't you count?" It's an endearing anecdote, one that we mortals cling to, perhaps out of wishful thinking that nature is somehow fair and democratic: surely what it gives to one man in the form of brains, it would take away in other ways. Einstein might have been the master of space-time, but here on Earth he was a naïve bumbler, the absent-minded professor. We want there to be a price for genius.

Exceptional parents know this only too well. They have countless opportunities to apply the concept, theory and reality of Relativity. To Exceptional Parents everything is Relative. They know that nature isn't fair and democratic, nor is the system we have created to address the flaws in nature always fair and democratic. They know that not every flaw in nature's repertoire has its compensation. They know that a grimace is sometimes welcome because it reflects a response. They know that a food-covered bib is compensation for the joy of oral feeding. They know better than most theoretical physicists that all things are relative in time, space and emotions. They know that while light rapidly travels around; the speed in which a physician returns a phone call is never fast enough. While Albert argued that the maximum possible speed of interaction in nature is the speed of the electromagnetic interaction, Exceptional Parents understand that the speed of interaction at an IEP meeting is slower than it needs to be. While Einstein accounted for the electrodynamics of moving bodies, Exceptional Parents ponder what it takes to get moving legislation that will provide continued support for their "aging out" children. And finally when Einstein referred to his theory of the Relativity of Simultaneity (which I think has to do with measuring time using the idea of simultaneous events) Exceptional Parents wonder why several things can't happen at the same time. Things like getting approval for ongoing physical therapy at the same time that approval for assistive communication devices should be passing each other in the mail (at the speed of the U.S. Postal Service).

Exceptional Parents understand Relativity and Reality only too well, while Einstein understood the reality of the Exceptional Parent when he observed that "Not everything that can be counted counts, and not everything that counts can be counted."

For Exceptional Parents no day is theoretical. EP

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

The Medical Nutrition hospitals trust.

Delivered to your door by someone you trust.

Thickened Apple Juice
NECTAR CONSISTENCY
DIABETISHIELD
RECOVER
Strengthen the Immune System For A Faster Recovery
Arginaid

Welcome to the *NEW* Resource® Medical Nutrition Center -
exclusively at www.resource.walgreens.com

Now you can have Resource® Medical Nutrition supplements that hospitals trust - conveniently shipped straight to your home by Walgreens, *The Pharmacy America Trusts®*.

Clinical performance, great taste

Health Care Professionals recommend Resource® Medical Nutrition because it works, but you'll choose Resource® for the way it tastes. All our products come in easy-to-use packaging, making Resource® as simple to enjoy as it is to obtain.

Our prices go down easy, too

Resource® Medical Nutrition products are priced competitively with other brands, and standard shipping is FREE on orders of $50 or more*. Plus, we'll rebate 50% off of one order, up to $20**.

Order now

Visit **www.resource.walgreens.com** or call **1-800-828-9194** to place your order or request a program catalog. You'll discover we not only promise the best Medical Nutrition - we deliver it.

NOVARTIS
NOVARTIS NUTRITION
To improve lives. To extend lives. To save lives.

Walgreens.com®
America's Healthiest Web Site™

We offer Resource® Medical Nutrition for the following health conditions:

General Nutrition Supplements • Before/After Surgery • Cancer • Children's Nutrition • Diabetes • Digestive Conditions • HIV/AIDS • Fluid Restriction/Concentrated Nutrition • Kidney Disease/Dialysis • Pulmonary (Lung) Conditions • Swallowing Problems • Wound Healing

As always, consult a Doctor or Dietitian regarding Medical Nutrition support.

Circle #57 or visit www.eparent.com/adinfo

*Subtotal excludes prescriptions, taxes and shipping
**Novartis Nutrition mail-in rebate offer
Not available in Walgreens stores.
© 2002 Novartis Nutrition Corporation

Search & Respond

S

Lip biting

My 7-year-old is delayed (1-15 translocation and partial deletion) but attends first grade and is doing much better than anyone ever dreamed she would. She finally made it to the fifth percentile on the growth chart at her 4-year-old check-up and almost overnight became obese. Her pediatrician says food is a "fixation" for her and has no real suggestions for helping her lose weight. Any suggestions would be greatly appreciated. She is VERY sedentary, loves to color and watch television. She also 'fixates' on picking scabs, picking her nose and right now has chewed her bottom lip until it looks like she has oozing fever blisters and she makes it bleed by biting it. I can make her wear gloves or socks on her hands but I don't know what to do to keep her from biting her lip—please help!

—KJ, 513, via EP Web Site

S

Wheelchair-friendly outdoor surface

My son has spina bifida and uses a manual wheelchair. We have a very large yard and he finds it frustrating that he cannot ambulate well in the grass. Has anyone used any kind of "path system" in their yard for a wheelchair that they've found works well?

—597, via EP Web site

S

Arthrogryposis and activities

My 4-year-old daughter was born with arthrogryposis and has had many surgeries, extensive PT, splinting and so on. She cannot walk, is in a power wheelchair and hardly has any arm movements. (She cannot hold, grab, nor scratch her nose.) Her orthopedist cannot guarantee us that she will be able to walk. She has no developmental delay. Are there any other parents with a child like this? If so what activities do you do in order to keep your child entertained?

—CS, 558, via EP Web site

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our Web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

Respond

R

Keeping the bed dry

SO (Feb. 2002) has a daughter with mental retardation and other disabilities who wets the bed nightly despite numerous precautions.

Our family had similar issues with my daughter who just turned 9. We found, however, that she was being "tripped" too frequently during the day and this was actually counterproductive to training the bladder to "stretch" and hold larger amounts of fluids; thus the bed-wetting. Check with your pediatrician, but bathroom trips should probably not occur more than every two hours for a young bladder, especially if she's not drinking large quantities of fluids.

—EH via e-mail

ERRATUM

In the May 2002 issue of EP, page 47 (Glossary of Movement Disorder Terms) the word "permanently" should be deleted in the definition of Botulinum toxin, as it is a temporary treatment.

Instant S&R

Hydrocephalus

S

My son is 2 years old. He was born with hydrocephalus, agenesis of the corpus callosum (ACC), arachnoid cyst, Cerebral palsy, and brain damage. He has had two fenestration surgeries (in which an opening is created) on the cyst. This cyst is almost the whole length of the right side of his head and approximately 5 cm wide. He suffers from tonic/clonic seizures. He doesn't chew and only says two words. He does sign up to 20 words. I am familiar with the hydrocephalus support groups and the ACC support groups, but I would like to speak with parents whose child has the same conditions (at least two of them) as my son. My son is going to have his third brain surgery soon.

—Maria via EP Web site

R

There is an online Arachnoid Cyst support group at http://www.egroups.com/group/arachnoidcyst.

—BS, via EP Web site

Informed Parents

Where Parents Keep Up To Date On Products For Their Children's Special Needs

New Products

NEW CATALOG
ORDER YOURS NOW

- Standing
- Gait Training
- Shower/Bath
- Seating Systems
- Transportation Safety

Call Today For Your

FREE CATALOG

1-800-336-7684

New Information

Therapist Tips

Education Series

SnugSeat®

BEST COPY AVAILABLE

Circle #62 or visit www.eparent.com/adinfo

Life threw Stephen a curve ball . . .

but that didn't keep him on the bench.

Key Statistics

Name:	Stephen
Age:	11
Diagnosis:	Cystic Fibrosis (CF), an illness that fills lungs with thick mucus and makes breathing difficult.
Favorite Positions:	Shortstop Pitcher
Throws/Bats:	RH/RH
Favorite Player:	Derek Jeter

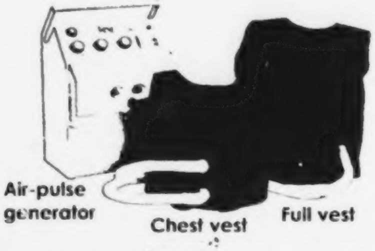
"Using The Vest system helps me stay at the top of my game."

Stephen, The Vest system user since 1998

Many people with respiratory complications, like Stephen, rely on The Vest™ airway clearance system for comfortable, effective airway clearance therapy.

More than **3,000** physicians have prescribed The Vest system for more than **20,000** patients with respiratory complications associated with cerebral palsy, muscular dystrophy, cystic fibrosis and over **200** other diseases and conditions.

For more information about The Vest system, call us at **800-426-4224** or visit **www.thevest.com**.



The Vest™
Airway Clearance System

So everyone can breathe a little easier®

www.thevest.com

The Vest™ and "So everyone can breathe a little easier®" are trademarks or registered trademarks of Advanced Respiratory. © 2002 Advanced Respiratory 501139 AA 06/02

Circle #77 or visit www.eparent.com/adinfo

Meet the Joneses

THE CORPS' FIRST FAMILY DISCUSS THEIR LIVES, THE IMPACT OF HAVING A CHILD WITH SPECIAL NEEDS, AND THEIR MARINES

By A.C. Strong, Sgt. USMC

LETTER FROM THE PRESIDENT AND CEO OF EP MAGAZINE

Since November 10, 1775, United States Marines have landed on the fiercest battlefields of this world. Often the first in and the last out, they have fought the fights, climbed the hills, secured positions and planted the flag. Their accomplishments are legendary and they are widely regarded as the most disciplined, respected fighting force in the world today. Because of them, we enjoy the freedom we so often take for granted to day. The term Marine conjures up thoughts of toughness, discipline and unfailing devotion to duty. But there is another, equally compelling side to the Marine Corps, and indeed all the men and women in our armed services, that is not very well understood and appreciated that we hope to shed some light on this in the following pages.

Today, the Marine Corps is headed by General James L. Jones, the 32nd Commandant of the Marine Corp. He is a man of uncompromising integrity, dedication and commitment, traits we have come to expect in all Marines. He is also the father of three sons and one daughter, Jennifer, with a profound disability. Together with his wife, Diane Jones, they have experienced first hand the daunting challenging task of parenting a child with special needs. Like all parents, we want the best for our children and the Jones's are no different.

Jennifer is thirty-one years of age and has Fragile X, a condition that often manifests itself with significant mental retardation and developmental delays. Parenting a child is a difficult task under normal circumstances. Parenting a child with special needs and three siblings gives clearer meaning to the phrase Exceptional Parent, and the General and Mrs. Jones have certainly earned that distinction. Overlay this with the duties and responsibilities of life in the military with frequent deployments, separations and relocations, and you begin to appreciate the extraordinary challenges faced by our men and women in the military, many of whom are parents of special needs children.

In this Special Report, EP focuses on the Exceptional Family Member Program (EFMP) of the United States Marine Corps. Our intention is not to stop there but in subsequent issues present the EFMP in the other branches of the Armed Forces, the Navy, Army, Air Force and Coast Guard. The EFMP is a remarkable program and there simply are no greater supporters of it than General and Mrs. Jones. In this initial segment, we hope to convey to you EP's first ever look at what one aspect of "taking care of our own" really means. We thought it was fitting and proper to begin with the Marine Corps. They are usually the first in, so beginning with them seemed the right thing to do!

One of the most well-known and striking visual images of the 20th Century is the Pulitzer Prize-winning photo by Joe Rosenthal of Marines and Sailors raising the flag atop Mount Suribachi at Iwo Jima on 23 February, 1945.

The image depicts courage, strength and honor and Americans have looked at that image for decades, recognizing it and the words of ADM Chester Nimitz, "Uncommon valor was a common virtue," as icons of that era.

During the recent inaugural Navy/Marine Corps Joint Exceptional Family Member Program conference, a medical officer used that image to illustrate the point that even some of those men needed assistance later in life for "special needs."

With a vested interest in programs for persons with disabilities, two individuals have taken their places as champions for the cause of special needs for Marines and other service members and their families – General. James L. Jones, Commandant of the Marine Corps and his wife, Diane.

The General and Mrs. Jones took time out of their schedule to be interviewed by EP magazine and its President and CEO, Joseph M. Valenzano, Jr.

"TOGETHER WE GROW" CONCEPT LINKS CORPS AND COMMUNITY SPECIAL NEEDS CHILDREN

Story by A.C. Strong and Cpl. Jose M. Montes

Special children need special support and the Marine Corps is reaching out to team with local organizations to help service families.

An example of this and the part played by its "Together We Grow" program, The Marine Corps teamed with an Oceanside, Calif., child-care provider to offer local-area military families with special-needs children a new choice for care.

Fostered by Gen. James L. Jones, Commandant of the Marine Corps, the concept of local and Marine Corps teaming has grown steadily in California and is being review at other bases throughout the world. Earlier this year, the Commandant was guest speaker at the opening ceremony just outside the Marine Corps Base Camp at Pendleton, Cal.

Located in a new 9,700-square-foot facility in the Mission Real Plaza in Oceanside, the center is the culmination of the joint efforts of Pendleton's Marine Corps Community Services (MCCS) and Special Care Inc., a San Diego-based health care company.

According to Terry Racciato, Special Care President, more than 1,100 Navy and Marine Corps service members assigned to Camp Pendleton are registered with the Exceptional Family Member Program (EFMP) and have family members with special needs.

The center offers preschool and day-care programs for both special-needs and mainstream children," said Racciato. "Serving up to 50 children at a time, program coordinators are hoping for a 50-50 mixture of children with and without special needs. The mix would boost social skills for all enrollees," according to Racciato.

This ratio "will help the special-needs child become better at dealing with life on his or her terms," said Racciato.

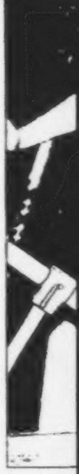
"The term 'special needs' covers a wide variety of medical, educational and emotional needs. The Together We Grow center addresses many of those needs, but especially focuses on the medically fragile – that being those children who need nursing care," said Linda Sheibler, Camp Pendleton exceptional family member program coordinator.

Each center is staffed by a team of teachers, nurses, occupational and physical therapists and others, to provide care for the children.

"Our goal is to make this (experience) as normal as possible," said Racciato. "So all the children learn to stand in line, wait their turn, play and paint together.

"That's the real advantage of our program. Our nursing care disappears into the background. The kids get to play."

The Camp Pendleton center is the second



BEST COPY AVAILABLE

General and Mrs. Jones have four children: Jim, age 34, Jennifer, age 30, and the twins, Greg and Kevin, age 27.

Jennifer, born in 1971, was diagnosed with Fragile X Syndrome.

Fragile X is the most common inherited cause of mental impairment, affecting one in 2000 males and one in 4000 females of all races and ethnic groups. It is caused by a defect in the gene called FMR1. In individuals who have Fragile X Syndrome, a defect or mutation shuts the gene down. This makes it impossible for FMR1 to manufacture the protein that it normally makes. Fragile X is also associated with a number of physical and behavioral characteristics.

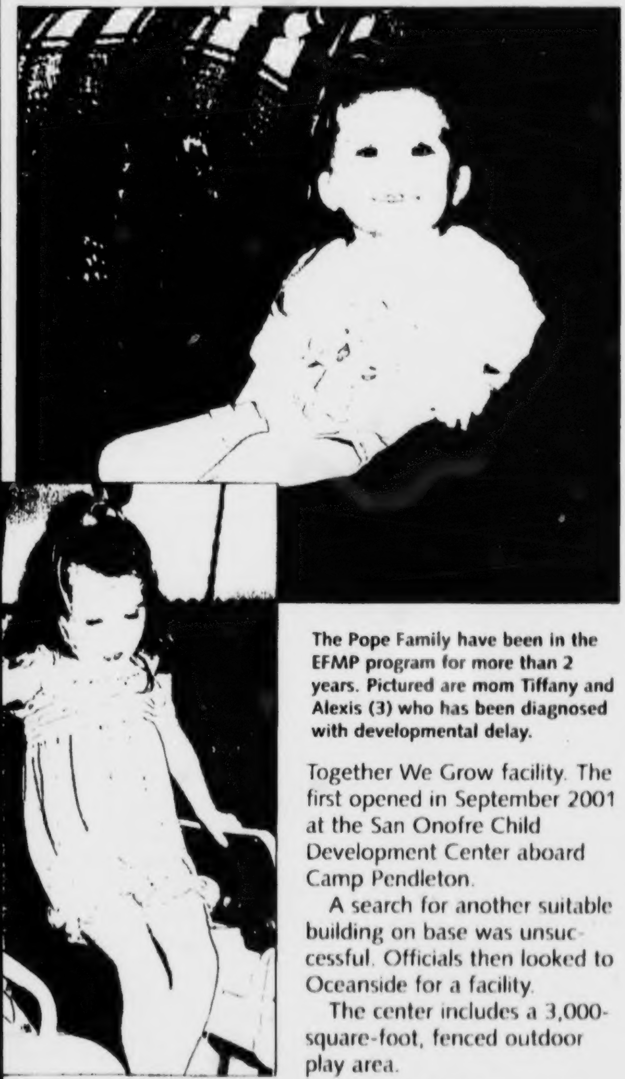
However helpful that may sound, it took years before the Joneses received that confirmed diagnosis. It wasn't until 1985, that the doctors were able to assess the years of information.

In the beginning, like most parents who face the challenges of a child with special needs, the Joneses just knew that something wasn't right.

Mrs. Jones was the first to notice Jennifer's symptoms and the lack of milestone-accomplishment.

Diane: "Jennifer was born with a partial cleft palate. She could still eat and drink. She just didn't seem to react

Continued on page 20



The Pope Family have been in the EFMP program for more than 2 years. Pictured are mom Tiffany and Alexis (3) who has been diagnosed with developmental delay.

Together We Grow facility. The first opened in September 2001 at the San Onofre Child Development Center aboard Camp Pendleton.

A search for another suitable building on base was unsuccessful. Officials then looked to Oceanside for a facility.

The center includes a 3,000-square-foot, fenced outdoor play area.

Each of the four rooms in the new Together We Grow center was named in honor of a child with special needs. One room, named "Jennifer's Jungle Safari Room," is named after Commandant of the Marine Corps, Gen. James L. Jones' daughter.

Jones told the audience about his life and the challenges of living with, caring for and nurturing a child born with a disability.

"When she was born in 1971, it was too difficult," said Gen. Jones. "I was a young captain then. I knew there might be programs out there for our situation, but I did not make an effort to find out.

"I looked at it as a situation my family should deal with by itself. I didn't want the Marine Corps to feel sorry for me."

Jennifer, diagnosed with Fragile X Syndrome, a disabling chromosome disorder, now lives in a group home near her family in the Washington, D.C., area.

"Don't do what I did, because you don't have to," said Gen. Jones. "It's not going to count against you to help your children gain their full potential."

At a recent speaking engagement in California, Mrs. Jones reiterated the point, "It doesn't matter what your label is, or what the disability is, everyone needs some type of support."

General Jones said caring for a child with special needs is an exercise in character building.

"I'm a better person for the experience of being the parent of a special-needs child, and our family is a better family for it," said Gen. Jones.

A third center, still in the planning stages, is to be built in Temecula, Calif. It is hoped that this will offer more options to service members in the surrounding area.

"We're hoping that with a triangle (of centers) around Pendleton, we'll be relatively accessible to the families coming into the base," said Racciato.

The EFMP is a mandatory-enrollment program designed to assist Marines and Sailors by addressing the special needs of their exceptional family members during the assignment process and to assist families in obtaining necessary care and assistance. Information about the EFMP is available on the MCCS Web site at: http://www.usmc-ccs.org/perssvc/efmp/efmp_main.html.

BEST COPY AVAILABLE

HARD MANUFACTURING

AGE APPROPRIATE BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas

The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

730

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #39 or visit www.eparent.com/adinfo

EP
has the
information an
"Exceptional
Parent"
like you
needs

EP
Exceptional
Parent

Your paid subscription
includes the
EXCEPTIONAL PARENT
2003
Annual
Resource
Guide,
which
normally sells
nationally for $19.95.

This invaluable reference tool is a "must-have" for exceptional parents

Save $5.00
by ordering on-line at:
www.eparent.com
For telephone orders call:
877-372-7368

Circle #199

Subscribe and be part of a network of "Exceptional Parents"

EP
Exceptional
Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: (www.eparent.com)

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______ Exp. Date ______
Name ______
Address ______
City ______ State ______ Zip ______
E-mail ______ Yes, I want more information to help me everyday.
Signature ______ E-mail ______

BJUL2

Subscribe and be part of a network of "Exceptional Parents"

EP
Exceptional
Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: (www.eparent.com)

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______ Exp. Date ______
Name ______
Address ______
City ______ State ______ Zip ______
E-mail ______ Yes, I want more information to help me everyday.
Signature ______ E-mail ______

IJUL2

Make someone a part of a network of "Exceptional Parents"

EP
Exceptional
Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95
☐ 2 Years (24 issues) $65.95
☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year.
Other foreign countries $57.95 per year.

PLEASE SEND MY GIFT OF EP TO:
Name ______
Address ______
City ______
State ______ Zip ______

THIS GIFT IS FROM:
Name ______
Address ______
City ______
State ______ Zip ______
☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______
Exp. Date ______
Signature ______

Save more money: Order off the Web: (www.eparent.com)

XJUL2

731

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

Exceptional
Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer life for themselves and for their children.

Exceptional
Parent's MISSION

IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS
Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional
Parent

www.eparent.com

www.abilitiesexpo.com

EXPO

Chicago Metro
Donald E. Stephens
Convention Center
August 16-18

New England
Bayside Expo Center
September 20-22

Northern California
San Mateo County
Expo Center
November 22-24

Education and *Equipment* to *Empower.*

Come **sample products** and **talk one-on-one** with service providers. As our guest you can attend **complimentary educational workshops** on everything from better sex to better jobs. Or perhaps you would like to see the power of new technologies in our **Access Ability Pavilion.** There are many options for you at **Abilities Expo.**

For more information please call (800) 385-3085 or (218) 723-9130 outside of the USA.
www.abilitiesexpo.com

BEST COPY AVAILABLE

abilities EXPO

PRESENT THIS COUPON FOR FREE ADMISSION

[ADMIT ONE]

Bring coupon to any **2002 Abilities Expo** and save the $5 on-site registration fee.
Coupon must be filled out to be valid and may be photocopied for additional registrants.

NAME: ____________________

ADDRESS: ____________________

CITY: ____________ STATE: ____ ZIP: ____________

For information call:
(800) 385-3085
(218) 723-9130 (outside USA)

Produced and Managed by:
ADVANSTAR COMMUNICATIONS

All events are wheelchair accessible.

© 2002 Advanstar Communications Inc. All rights reserved.

Circle #17 or visit www.eparent.com/adinfo

> *"We deceive ourselves when we fancy that only weakness needs support. Strength needs it far more."*
>
> — Madame Swetchine, 16th Century author.

continued from page 15

to sounds and perceive that you were talking to her, or make eye contact. We had only one other child, who was three years older. Then, at about her 6 months checkup, one of Jennifer's doctors said she had a sixty-five percent chance of mental retardation.

"I had a hard time dealing with it, especially the part about being a 64% chance. I was struck by the precision and imprecision of it all." We tried all the different hospitals – Bethesda, NIH, Johns Hopkins—and basically no one ever really made a diagnosis."

"The amazing thing was, in the beginning, I was devastated and Jim was very much in control. The expectations that were given to us were that she would never walk or eat," Gen. Jones said. " They told us she will never feed herself," Diane added. "It was suggested that we put her in an institution. General Jones quietly said "We simply refused to do that."

"I would not ever entertain the notion of 'never,'" Gen. Jones recalled. "They told us she would never do this, never do that—and she did them all."

Still young by Marine Corps standards, then Capt. Jones and his family struggled to make sense of the doctors' impression that the Joneses were in denial because they refused to place Jennifer in an institution.

Diane: "One of the reports that came back from Hopkins said 'the father (Jim) is having a hard time dealing with this,' said Diane. 'They wrote him up like he was floundering, but he was actually the one who was like a rock.'"

Gen. Jones: "They said I was in denial. For every time they said she wouldn't be able to do something, I said 'but she already is doing it.' There was no question in my mind that I couldn't part with this child." Diane: "Yes, and here was this positive attitude that we will not institutionalize this child."

In 1971, pre-dating 1975's Individuals with Disabilities Education Act (IDEA) and 1990's Americans with Disabilities Act (ADA), Jones didn't know if there were programs available to assist his family and didn't want anyone to feel sorry for him, so he and Diane pulled together and faced obstacles as a strong family unit.

Gen. Jones: "But we floundered. We were really novices and there were no programs we were readily aware of."

Diane: "Yes, it was all new."

Gen. Jones: "There wasn't much in the military and we are talking the 70's here. They were reactive, but they weren't proactive. (However) the early intervention people were proactive with us."

Both General and Mrs. Jones are strong advocates for early intervention programs. "There is no question but that they work."

The family moved from Maryland to Fairfax, Va., because Fairfax County had just started Infant Stimulation/Early Intervention programs and 1-year-old Jennifer started the special programs and preschools that were available there.

Diane: "He is right. There really was nothing in the military," said Diane. "It was all new, even in your county and local states. Because of Public Law 94-142, they were just getting into infant stimulation and all the other interventions. You didn't have great niches and other people around that could refer you to an agency or something."

Gen. Jones: "Absolutely."

Diane: "That is why the Exceptional Family Member Program is so important. I think it is important now to expand beyond—to have a support resource for Marines, because that's our family—our military family."

"But you asked how it impacted us as a family? Well, Jim would go out into the community and never be concerned with people who would stare or youngsters who would just point. I, on the other hand, had a very difficult time. It broke my heart; it was just the pain of it. I am, after all, a mother. I couldn't understand people referring to her as 'retard,' or staring or glaring."

Diane: "I thought this was the way the Lord said, 'Okay,Jennifer is your kid. Go back into special ed.' So I went back for my graduate degree in special education." Gen. Jones added: "While I was overseas for a 13-month assignment."

With four children under the age of six, Diane relied heavily on her own strength and the assistance of her parents who were nearby. Gen. Jones: "When I went overseas I was a Captain, and in those days, as you recall, tours of duty in the Marine Corps were 13 months long. The Marine Corps let me stay home through the first—we had a complicated birth, so they let me stay home for 90 days after the twins were born. When I left, our oldest son was 6, Jennifer was 3 and the twins were 3 months old, and Diane went

Continued on page 22

THE CHANGING FACE OF MILITARY LIFE

Napoleon once said, "Soldiers win battles and Generals get the credit." What he didn't mention, however, is that most soldiers and generals have families who are affected by military life.

This is especially true today. Two decades after becoming an all-volunteer military, 55% of all service members are married and have over 1.2 million children. The majority of children (73%) are 11 years of age or younger, with 39% below the age of six.

This profound demographic shift portends greater diversity of family structures, each with unique stresses and needs. The number of single parents is 6% of all personnel, up from 3.7% in 1989. One significant consideration is that today 20% of female service personnel are in joint service marriages as compared to 4% for male personnel. Overall, women represent about 15% of the entire military population.

TODAY'S MILITARY FAMILY:
Today's military family faces a lifestyle that comprises a higher operations tempo as well as more frequent deployments and thus increased family separations as the result of more frequent relocations and more varied types of military assignments and missions. These factors create stresses and challenges for families that, if they are not able to be managed successfully, can impact on readiness.

Dual military families and single parents face issues that require additional planning. This is especially true if they have a child with special needs. At present, there are 34,732 dual military couples with children and 83,564 single parents in the military. The planning, child care arrangements and emotional issues regarding these military children gained national attention in the Persian Gulf War when, for the first time in U.S. history, both mothers and fathers deployed.

Today, the military community must have the objective of strengthening local resources as a major focus. Coordinated, community-based efforts are needed to support families as the nation's defense budget and the ranks of military personnel decline.

ISSUES AND CHALLENGES:
The principal issues faced by today's military family may best be summarized as follows:

- ☆ New missions, plus the added threat of global terrorism, translate into an added workload on an already overburdened force that is stretched across all continents.
- ☆ Higher family stress, especially if that family has a child with special needs.
- ☆ Specialized technical skills are in constant demand and short supply.
- ☆ An increased reliance on military reservists with specialized skills.
- ☆ Both mothers and fathers and joint deployments must be dealt with when considering families caring for children with special needs.

TAKING CARE OF OUR OWN:
The military, especially the Marine Corps, prides itself on the time-tested tradition of taking care of its own. And well it should. They do take care of their own and they do look out for each other. But the increased stresses mentioned earlier will place an expanded burden that will require the military to think a bit outside the box and focus on greater community involvement. Members of the military will need to seek greater access to quality information that can help their families cope with the challenges of raising a child or children with special needs.

The military can and should be viewed as an extended family. Ask any Marine, on active duty or not, and he will likely respond in the present.... "I am a Marine". The military does for its dependents what all good families do; it functions as a special type of family, a unique group of people who love, care and support one another.

The functions of a family include educational, recreational, emotional and economic support that is reinforced by a sense of pride and strength in caring for each other. Fortunately, inside our military, there exists the Family Support System of the DoD and it provides a spectrum of services that help military families cope with the issues and challenges they face in this fast-paced, ever-changing world. Among the issues addressed by the Family Support System of the DoD are the following:

- ☆ Relocation Assistance
- ☆ Transitioning to a Civilian Career Assistance
- ☆ Personal Financial Management
- ☆ Exceptional Family Member Program Services (EFMP)
- ☆ Spouse Employment Assistance
- ☆ Chaplain Assistance
- ☆ Emergency Financial Aid
- ☆ Medical and Dental Services
- ☆ Information & Referral Services
- ☆ Child & Youth Services
- ☆ Support During Duty Separation
- ☆ Mental Health and Substance Abuse
- ☆ (Pre-Deployment, Deployment Services and reunion Support)
- ☆ Family Life-Skills Education
- ☆ Recreation & Fitness
- ☆ Volunteer Resource Management
- ☆ Primary & Middle Schools
- ☆ Health & Wellness Centers
- ☆ Family Advocacy

BEST COPY AVAILABLE

MARINES' FIRST LADY

EXCEPTIONAL FAMILY ADVOCATE

As First Lady of the Marine Corps, Diane Jones has been instrumental in improving the quality of life for all Marines. She has been especially concerned about Marines whose family members are in the Exceptional Family Member Program. Mrs. Jones helped to create the Marine Corps Family Readiness Committee as a voice and advocate for all the family and volunteer programs.

During the past three years, she has fostered a Committee for Persons with Disabilities comprised of family, base and community representatives on every major Marine Corps base. This attention to support services and private partnerships has resulted in improved accessibility, childcare, respite care and recreation options. A private fund was established to assist families in affording equipment and services otherwise not available to Marine personnel and their families.

When the Department of Defense steering committee held its first summit this year to explore ways of standardizing this program throughout all the military services, she was an active participant.

Besides testifying before the House Committee on Education, she has served as guest lecturer at numerous graduate programs.

The mother of four, including a daughter with fragile X syndrome, Mrs. Jones holds a BA and MA in Special Education from George Mason University.

continued from page 21

back to graduate school. If it hadn't been for her parents, we never could have done it."

Aware that whatever she was feeling she would project to her children, Diane was as careful as possible. However, a parent cannot be a permanent shield. So all four children shared in the responsibility, the joy and the pain.

Diane: "It became incumbent on them to pick up more responsibilities. From early on, I would need help with this or that. We had many emergencies with Jennifer, which would have us rushing to the hospital in the middle of the night." But our sons always treated Jennifer like anybody else. I am sure that when people would stare or make fun of her, it broke their hearts."

Gen. Jones: "They were pretty strong."

Diane: "They are very strong."

With all the responsibilities, the boys were never jealous of the attention that Jennifer received. They just pitched in where they were needed.

At the age of three, Jennifer developed a mysterious illness that caused her to vomit for no apparent reason. According to Gen. Jones, doctors at the National Naval Medical Center, Bethesda, Maryland could find nothing. They ran tests, and even did several surgical procedures which solved nothing.

The boys were in an environment in which their sister was being taken to the hospital regularly and they were under stress.

Diane: "...The positive side is as long as the boys were in school, whenever we would go in for parent-teacher conferences, they would always say the same things about the boys – always very kind and thoughtful to others. They always were. Even though they were class leaders and athletes in their own right, they always reached out to the kids who weren't included to make them feel as if they belonged. They have always been very protective of people who aren't quite as big, aren't quite as fast, aren't quite as included in the main group. We have always attributed that to the fact that they have a sister who is special. They learned some of life's valuable lessons early on and it has paid off for them."

The family has gained the ability to carry over their personal strengths and give back to the community. However, Gen. Jones wasn't always as confident in how to deal with the challenges.

Gen. Jones: "Well, let's be real clear about this. I am an example of what not to do. I did that when I was a young officer; I had the impression that this (Jennifer) was my problem, our problem. I didn't want special treatment and I certainly did not want my career jeopardized because of my own family problem."

"It wasn't that I was embarrassed. Obviously, I have not been. I am very proud of Jennifer and happy that she is a part of our family. The issue was that I wanted to stay on in the Marine Corps. I wanted to seek the same experience that all my peers had. I wanted very much to be a company commander. I very much wanted to be a battalion commander. I felt whatever difficulties we had in the family we would, WE would fix them."

"I resisted offering myself up as a candidate for any kind of special assistance. I am like any other Marine... I did not want any special privileges. The EFMP is a command registry program, it's not a support program."

In the past, the EFMP wasn't promoted. Enrollment in the program is mandatory under Marine Corps Order P1754.4A, but some service members avoid enrolling in the program because of common misconceptions such as "I won't be able to re-enlist." Or, "My career will be flagged and I will not have promotional opportunities"

"Our way of life can be challenging

and stressful to our families," said Gen. Jones, in a white letter dated Jan. 25, 2001. "This is particularly true for families who have special needs such as severe medical conditions or special educational learning requirements."

In the letter, the Commandant directly charges Marine Corps leadership to recognize and emphasize their roles to create an informed and understanding environment. He says, "Leaders, at all levels, need to not only be aware of EFMP, but actively refer Marines."

"Misconceptions and concerns continue to be pervasive about the EFMP as it relates to a Marine's career progression. Your help is needed to spread the truth and dispel these perceptions," said Gen. Jones to Marine Corps leadership.

The program is based on a number system, one through five, five being the families with the most impaired individuals, who are not all children. Spouses and parents also make up a good percentage of the numbers.

Diane: "They represent the same percentage that the regular (civilian) American society would be. Therefore, there was no reason on earth for our people who go overseas - a young Marine who wants to deploy - and be told there are no services for the disabled. We did the same thing. Jim went overseas all the time. I chose to stay back because of Jennifer's medical needs, not knowing that that's what really would have happened in the program anyway in those days.

Gen. Jones: "I will give you an example of the higher end of things. We have a command selection process in the Marine Corps and the last couple of years one of the colonels was selected for a command in Japan. Through the screening process, we found out that his wife is allergic to a certain type of shot that is given to anybody who goes for duty in Japan to prevent contraction of a disease that is prevalent in Japan. She can't take the shot medically. Now in the old days, we probably would not have known that. Now that we do, we are able to talk to the family and say, 'Look medically this is dire. You need this shot because the probability of contact is pretty high. Either way, if you don't have the shot or if you take it, you are putting yourself at great risk.'

Without changing the colonel's orders, we just moved him from Okinawa to another similar command in North Carolina.

That's the kind of participatory relationship we want to have so we can allow Marines to continue their careers without fear of any kind of a stigmatization and without fear of being treated 'specially.'"

General Jones believes that there is always another way to work around (problems) and it doesn't have to make anyone feel sky-lined, guilty or different.

Gen. Jones: "We have all kinds of different needs. Sometimes it's not associated with disability. Sometimes it's an elderly parent who would not be able to survive without a family member somewhere close by on the Eastern seaboard. If we can do that for our people, we should do that."

Diane: "One of the things, piggy backing on that, is our Committee for Persons with Disabilities and access to care and information on our bases. We discovered this committee very early on at Camp Lejeune in North Carolina, started with parent advocacy and parent initiative. We were so impressed because what that did was bring base representatives, the families, the people with disabilities themselves and the community together. This committee was even organized with bylaws and was not a gripe session. It offered an opportunity for all to share issues, concerns, best practices, etc.– anything and everything that warranted attention. Even accessibility was brought up. As a result, we (the Marine Corps) have implemented this committee in some format on all our major bases and stations.

"What has it done? To name a few innovative results, we now have beach wheelchairs, handicap accessible pontoon boats, adaptive pool lifts, handicap accessibility to buildings, parking and also, outside of accessibility issues, supports such as therapeutic recreation, childcare, and respite care—those things that allow individuals to have normal lives."

Continued on page 24

EXCEPTIONAL FAMILY MEMBER PROGRAM (EFMP)

WHAT IS IT?

The Exceptional Family Member Program (EFMP) is designed to provide assistance to active duty personnel with family member (s) who have special needs before, during and after relocation due to Permanent Change of Station (PCS) Orders.

An Exceptional Family Member is an authorized family member (spouse, child, stepchild, foster child or dependent parent) residing with the sponsor who may require special medical or educational services based upon a diagnosed physical, intellectual or emotional need. This includes conditions such as asthma, cerebral palsy, mental retardation, dyslexia, ADD/ADHD, autism, oppositional defiant disorder, depression or other rare disorders. Disabilities may range from mild to severe.

BEST COPY AVAILABLE

continued from page 23

The EFMP provides program coordinators at each base and station to manage and monitor the assignments. They themselves become informational resources. They work with the community to access outside assistance for partnership support. This is evident in programs such as "Together We Grow" at the Marine Corps Base Camp Pendleton area. (see accompanying story)

Gen. Jones: "The Marine Corps has 15 major bases and stations around the country. Virtually all of them have strong relationships with the local communities. In many cases Marines either retire or leave service and stay on. So the relationship between the community and the bases not only encompasses careers, but continues after them.

Diane: "We can't be in this box anymore. You have to look at alternative options and they are not all options that require the military to provide everything, but they are partnerships and agreements."

An illustration of this is another issue involving the community and the service member: military housing and the public/private venture. Historically, there never seems to be enough housing. According to the Commandant, under a new program which he has spearheaded, the Marine Corps is now contracting with builders provide the housing and maintain the property and is paid "rent" out of the Marine's basic housing allowance. This will provide more housing availability, including ADA compliant units.

Diane: "The public/private venture is so key because I believe we could do the same in child care. That's my goal."

"This is another aspect that is important too. The Corps has a single Marine program and the irony is, the perception is one of single Marines who are all young corporals out on ships. Today you have divorcees, widows and widowers and you have single parents with special needs program requirements. The entire structure of the armed services has changed versus what things were like twenty years ago."

Programs are beginning to shape up on bases and stations which provide for that specific need, and EFMP coordinators have access to information about community and respite opportunities.

General Jones' Brilliant Career

General James L. Jones attended Georgetown University's School of Foreign Service graduating with a B.S. Degree in 1966.commissioned a second lieutenant in the Marine Corps, he was sent to the Republic of Vietnam, serving as a Platoon and Company Commander until June of 1968.

He rose steadily through the ranks of the Marine Corps, attending the National War College, serving as Military Liaison Officer to the United States Senate, and Commanding General, 2d Marine Division. He was assigned to the Office of the Chief of Naval Operations, Military Assistant to the Secretary of Defense and now is the 32nd Commandant of the Marine Corps. General Jones' decorations include the Defense Distinguished Service Medal; Silver Star medal; Legion of Merit with Four Gold Stars; Bronze Star Medal with Combat "V" and the Combat Action Ribbon. He has also received the S. Robert Cohen Annual Achievement Award given to the person who "best exemplifies the spirit of the Jewish Foundation for Group Homes and its commitment to independent living"

Gen. Jones: "I think, fundamentally, what we are trying to do is gain knowledge and support from the community and recognize that there are a lot of people who can help our Marine Corps Family. However, what we are talking about is serving the group that needs special focus on that".

Diane: "That's what you (EP) do. You help make people aware of new technology, new treatment options, etc., and our Marine Corps family needs access to this kind of information as much, if not more, than the families who currently subscribe to your publication. I'd like to see EP on every Marine Corps Base in the U.S."

"It's a fact of the human condition. We all need help at some point. But it often holds out great benefit to us and the nation. If we invest a lot of money training these young Marines, hopefully the best will stay with us. Then it is incumbent upon us to try to do those things that can help them fulfill their potential as Marines. It is also the right thing to do!"

Diane: "In the military, we have programs for counselling, religious services, domestic violence, physical fitness, education, spousal employment – all under the umbrella of family readiness. We have them all. If you just expand this program just a little more, it fits the whole description.

"We were able to establish a Family Readiness Committee which represents family programs and acts as a voice and advocate for them, to include the Exceptional Family Member Program. It comes down to this: we have young people joining the Marine Corps and we want to keep the majority. So you offer them the best you can that allows their families to have a normal life."

And, as with all families, "normal" is different for each. The Jones family just happens to encompass several thousand Marines. EP

(More information about Fragile X Syndrome is available in this issue's Organization Spotlight and on the National Fragile X Foundation Web page at: http://www.fragilex.org/home.htm.)

The Center for DISCOVERY

The Center for Discovery is certified by New York State through the State Education Department, the Department of Health and the Office of Mental Retardation and Developmental Disabilities (OMRDD); and by the Commission on Accreditation of Rehabilitation Facilities (carf).

Visit us at Booth #730 at The World Congress & Exposition on Disabilities in Orlando, Florida — October 3-5, 2002

Please read the four-part series, "Transitions: Informing, Empowering and Keeping Parents Involved," (June through September) currently appearing in Exceptional Parent Magazine.

Don't miss the special presentation, "Transitions: Informing, Empowering and Keeping Parents Involved," at the WCD (Oct. 4, at 2:00 p.m.) that will address the issues raised in the four-part EP series.

Be sure to attend the presentation at the WCD (Oct. 3, at 3-5 p.m.) highlighting the outcomes of The Center for Discovery 's International Summit, entitled "Disabilities: Sharing Visions for the Future" that was held at The Center this past June.

The Center for Discovery, a nationally-renowned prep school for children with significant disabilities (including multiple disabilities, medical frailties and some behavioral concerns) recently opened several new, small, universally-designed residences.

Located near Monticello, NY in the picturesque Catskill Mountains, just two hours northwest of New York City, The Center features a nature-based program that challenges children, and their families, to work with us to provide the finest educational, clinical, social and residential opportunities available anywhere.

We may just be
the right program
for your child.

Call our Admissions Office at (845) 794-1400, extension 1444 for information and/or to arrange a personal tour and see *discovery* in action.

Ask for our new video.

Box 840 / Harris, NY 12742
845-794-1400, extension 1444
email: admiss@sdtc.org

Visit our websites:
www.thecenterfordiscovery.org
www.discoveryifi.org

BEST COPY AVAILABLE

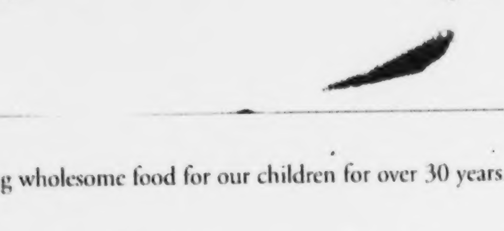
Circle #68 or visit www.eparent.com/adinfo

Preparing wholesome food for our children for over 30 years.

Try one of our eight varieties and let us share with you the

peace of mind

and well-being that comes from EDENSOY Organic Soymilk.


EDENSOY Light
ORGANIC SOYMILK
EDEN
EDENSOY EXTRA
ORGANIC SOYMILK
EDEN
EDENBLEND
Rice & Soy
EDEN
EDENSOY
ORGANIC SOYMILK
EDEN

Save 50¢

On any EDENSOY®
Single liter or 3 pack

Consumer: Coupon good only in USA on purchase of brands/size indicated. Void if copied, transferred, prohibited or regulated. Retailer: Eden Foods, Inc. will reimburse you for the face value of this coupon plus 8¢ handling if redeemed in compliance with our redemption policy. Copy sent upon request. Invoices proving purchase of sufficient stock to cover coupons must be shown on request. Face value .001¢. Mail coupon to: CMS Dept. #24182; One Fawcett Drive; Del Rio, Texas 78840.

Redeemable at retail stores only.

10633

EDEN.

Manufacturer's Coupon	Expires 10-31-02

5 24182 00050 9 (8101) 0 10633 1002

790

© 2002 Eden Foods, Inc.

Call for a free Edensoy brochure **888.424.EDEN** or visit us online **www.edenfoods.com**

Circle #32 or visit www.eparent.com/adinfo

The National Fragile X Foundation

By Jeffrey S. Cohen and Robert M. Miller

Established in 1984, The National Fragile X Foundation unites the fragile X community to enrich lives through educational and emotional support, promote public and professional awareness, and advance research toward improved treatments and a cure for fragile X syndrome.

BEST COPY AVAILABLE

Fragile X syndrome is the world's leading cause of inherited mental impairment and the community of individuals touched by fragile X is as diverse as it is large. Nearly 1 million families in the United States are touchedby fragile X, either as carriers or affected individuals. Worldwide, the number is a staggering 20 million people. The fragile X community encompasses individuals from every country, race, religion and ethnic background.

Tracey (left) and Mikayla (right) share mother and daughter smiles

The diagnosis of fragile X syndrome cannot predict the future of the child. Individuals with this single-gene disorder function across a broad spectrum of intellectual, social and emotional levels, from normal to mildly impaired to profoundly impaired. Although the diagnosis is made with a simple blood test and can even be made in utero, the degree of a child's impairment and his or her future success cannot be

continued on page 28

continued from page 27

predicted. There are individuals who are technically only carriers but seem to be significantly affected, while others, who are by definition "fully affected," function at a fairly typical level.

Since the National Fragile X Foundation (NFXF) is often a family's first stop in their quest for answers, we strive to provide the educational and emotional support so critical to surviving this trying time in the life of a family. Person-to-person support is a toll-free phone call away (see contact information on page 30) and in most states other parents and knowledgeable professionals are organized by the Foundation into resource groups, Centers and parent contacts who can provide personal support. The most common message provided to families by the staff of the Foundation and by the parent support network, is that with the proper intervention their children can be participating and contributing members of their families, schools and communities. As obvious as this may seem to those in the professions of special education and therapy, it zeroes in on the deep anxiety that many parents feel about their child's future. The Foundation provides resources to meet the needs of families confronted with the reality of fragile X such as books, pamphlets, newsletters, videotapes and a web site. Not only are these materials filled with the science of fragile X and its medical treatment, but they also offer everyday, practical advice.

Because so little is known about fragile X within the broad medical, educational and public communities, the National Fragile X Foundation works to increase public and professional awareness. Television public service announcements (PSAs) are distributed to stations across the country. Recently, a truck-driver from Texas learned about us after receiving a call from his wife who excitedly told him about the Foundation's affiliated parent support groups in their area after viewing our PSA and learning that she was not the only one in the world who had a child with the syndrome. Educational resource materials are published to help both parents and teachers successfully educate children with fragile X along with their non-affected peers. The Foundation is currently completing the first year of a two-year education project to create a classroom lesson-planning guide designed to help teachers improve inclusion of children with fragile X in their classrooms.

The family shares there love with a hug. Pictured from Left to Right are Tava (10), Tracey (Mother), Olivia (17), Mikayla (7) and David (Father)

Crucial to the Foundation's mission is its biannual International Conference. The National Fragile X Foundation is holding its 8th International Fragile X Conference in Chicago on July 17-21, 2002, with approximately 700 parents and professionals expected from more than 20 countries. Leading scientists from around the globe will gather to share their findings and challenge each other to do more, find more and help more. These conferences are designed to bring together the leading minds in the fields of medicine, molecular biology, genetic and mental health counseling, occupational therapy, speech and language intervention, and education with parents, families, direct support professionals individuals with fragile X.

The NFXF's International Conferences strive to create a climate where members of the fragile X research community take a more collaborative direction and where small, incremental steps are shared with colleagues in the advance towards more effective treatments and an eventual cure. Best practices for teachers, speech pathologists and occupational therapists are also featured, making these conferences truly one-stop, cutting-edge resources for all concerned with fragile X.

Perhaps the most enriching results of their international conferences are the lifelong friendships established among the families and professionals who share the bond of fragile X. Members of the research community are particularly motivated in this quest by the personal relationships they establish with families during these conferences. Like many of the challenges faced in life, the challenge of fragile X is better met when those it impacts band together to support and learn from one another.

It is this challenge that drives the third focus of the Foundation: to advance research seeking improved treatments and a cure for fragile X syndrome. The Foundation supports research on different types of therapy —speech, occupational, behavioral— and best educational practices. Fully understanding the promise that the Human Genome Project holds for the eventual cure of many genetic conditions, the Foundation also funds promising scientific research. Fragile

continued on page 30

Shopping solo

Chase, a 19-year-old with autism, can now tolerate the noise and overhead music in the store. He's learned to ignore the candy and chips, to choose nutritious foods without the help of props or pictures. Back at Heartspring, he neatly puts the groceries away and sets the table. After dinner he washes and dries the dishes. With only a little supervision. And with a lot of pride.

HEARTSPRING™
SCHOOL
Finding New Ways for Learning
8700 East 29th Street North • Wichita, Kansas 67226
call 1-800-835-1043
www.heartspring.org

Circle #20 or visit www.eparent.com/adinfo

continued from page 29

X is seen by many in the research community as a "portal" condition, based upon the widely-held belief that unlocking the secrets of fragile X will lead to breakthroughs in the understanding and treatment of many other similar and related conditions. In an effort to attract new, young researchers to this exciting field, the Foundation provides summer fellowships for students working with established fragile X research programs.

Medical Aspects of Fragile X Syndrome

Fragile X syndrome is the most common genetically inherited form of mental retardation currently known. In addition to intellectual disability, some individuals with Fragile X display common physical traits and characteristic facial features, such as prominent ears.

Children with Fragile X often appear normal in infancy but develop typical physical characteristics during their lifetime. Mental impairment may range from mild learning disability and hyperactivity to severe mental retardation and autism. This genetic syndrome is caused by a defect on the X chromosome. Because of scientific advances, improvements in genetic testing and increased awareness, the number of children diagnosed with Fragile X has increased significantly over the last decade.

Scientific research efforts must include not only private funding but also government funding in order to succeed. The Foundation is a member of the Coalition for Children's Health (CCH), an advocacy group based in Washington, DC, that promotes a wide range of children's health issues. Through the CCH, the Foundation participates in efforts to educate members of Congress about fragile X and urges them to increase funding for research and treatment. In 2000, the NFXF participated in an effort which culminated in the passage of a landmark law known as the Children's Health Act of 2000. This Act provided funding for research into a wide range of conditions affecting children's health, including fragile X, and the establishment of three fragile X research centers. Another noteworthy accomplishment in 2000 was the proclamation by Congress declaring July 22 as National Fragile X Awareness Day.

These accomplishments are made possible by the generous and enthusiastic support of the worldwide community of fragile X families and professionals. While similar in many ways to other disability groups, the fragile X community is unique in its struggle to raise awareness of this common yet little-understood condition.

It is the enthusiasm and determination of parents and professionals to make a difference in the lives of children and adults with fragile X that drives the National Fragile X Foundation in its efforts to educate, raise awareness, promote and support research and provide timely, meaningful, relevant resources.

Jeffrey S. Cohen is the president of the National Fragile X Foundation, and Robert M. Miller is the Foundation's executive director.

We're up to the challenge!

For Information and Support Contact:
The National Fragile X Foundation
PO Box 190488
San Francisco, CA 94119-0488
ph: 800-688-8765 (toll free)
925-938-9300
fax: 925-938-9315
email: NATLFX@FragileX.org
Web site: http://www.FragileX.org

HDIS

Convenient Home Delivery of Bladder Control Products

Try Tranquility® All-Through-the-Night Disposable Briefs, FREE!

FREE Sample Offer!

More absorbency means more comfort and protection.

- Extraordinary absorption capacity.
- No need for multiple changes through the night.
- Latex-free construction.
- Wide range of sizes (including youth) to assure a comfortable fit.

Call now for your FREE sample!
1-800-2MY-HOME®
(1-800-269-4663)

"We're happy to answer any questions you might have."
- Mary

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

©2002, HDIS 024-131

Circle #38 or visit www.eparent.com/adinfo

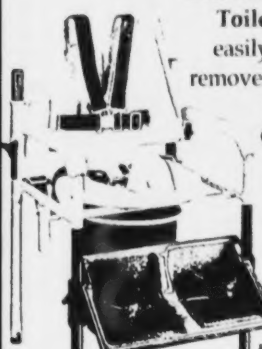
Sharing the Caring

Sally, 40 lbs. and 45" tall, in the #8600 Reclining Bath Chair with #8875 Head Pad

Columbia offers you solutions to the daily challenges of bathing, toileting and transporting your child – *with comfort, safety and ease!*

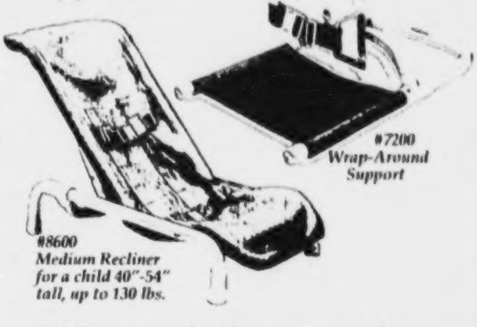
You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

☐ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.



#5800 Hi-Back Positioning Commode for junior adults

☐ At bathtime, our popular **Wrap-Around Bath Supports** and **Reclining Chairs** allow your child – and you – to enjoy the bath.



#7200 Wrap-Around Support

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

☐ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.–yet weighs only 11 pounds! Comfort, style and adjustability have made it the No. 1 choice since 1986.

#2000 Car Seat

Why do these products work so well?
Much thought and care go into the design of each Columbia product. We make each item in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, proven in real life. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

COLUMBIA
SHARING THE CARING

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG
Columbia Medical Mfg. Corp., Dept D2, P.O. Box 633, Pacific Palisades, CA 90272
Visit our web site at http://www.ColumbiaMedical.com

Circle #27 or visit www.eparent.com/adinfo

INDEPENDENCE for Teens During Summer Break:

Techniques to Reinforce Life Skills at Home

By Carolyn O. Cantu, MS, OTR

Summertime...

In most homes across America, the relaxed summer months are time when young people tend to forget the skills they learned during the school year. This is often the case with independent living skills acquired by exceptional teens. A natural reaction occurs: the more independence skills slide, the more parents tend to pick up the slack. All too often, summer is draining for parents and boring for teens. To prevent this situation, parents can adapt special-education and therapeutic techniques to the home environment. These strategies can be an effective means of reinforcing independent life skills learned during the school year, maintaining hard-won gains.

How the pros do it

Throughout the school year, special educators and therapists commonly use daily routines, high structure, organization, visual and auditory prompts to teach life skills and reduce inappropriate behavior. Though the list may vary from state to state, and even among school districts within a state, life skills are often categorized for presentation by domain: self care/personal care, home living, social/communication, community-based instruction, vocational, functional academics, recreation and leisure. Behaviors such as impulsivity, lack of initiative, inability to complete tasks, memory difficulties, distractibility, disorganization, stress and anxiety interfere with independence skills in both classroom and home environments. The process of reducing the influence of such behaviors and promoting independence involves two distinct steps: analysis and synthesis.

Activity Analysis

Activities and how they are performed must be evaluated before life skill strategies can be applied effectively. School-based occupational therapists and special educators identify which component(s) of a functional or academic activity is a stumbling block in a student's path to success. The Material, Process, and Product Analysis is one of the easiest methods for activity analysis to adapt for home use. Selected from many methods taught in occupational therapy curricula, this design is particularly simple, quick and effective for parents to modify.

An example of a self-care activity analysis

Category: food preparation. Activity: making a peanut butter and jelly sandwich and glass of milk for lunch.

Material Analysis (items needed for task to be completed): jars of peanut butter, jelly (or honey), bread, work surface (eg, a cutting board), plate, knife or spoon, napkin, glass or plastic cup and milk.

- What materials are necessary to accomplish this activity?
- Are they familiar to the teen?
- Are ingredients and materials easy to locate and transport to the preparation area?
- Are visual prompts needed for the teen to locate the materials independently?
- Are any utensils needed that are potentially dangerous?
- If so, what does the young person already know, what needs to be reinforced, and what information needs to be added?
- Is there any substance or material in this activity that causes tactile defensiveness in the teen, resulting in refusal to touch the materials or substance? How can the activity be adapted so that it can still be accomplished even with this substance/material?

Process analysis (steps the teen must execute in sequence to complete the sandwich):

- Is the teen familiar with the location of all ingredients and utensils?
- Can she or he walk or wheel to the location, open the cabinet or drawer, and reach and gather the necessary items?
- Are visual prompts (pictures of utensils or written labels of items) needed as location reminders?
- Can the teen safely transport items from the refrigerator, cabinets or drawers to the preparation area? If not, what assistive devices or equipment (eg, a rolling kitchen cart) may enable independence?

- Does the teen have the grasp and dexterity necessary to open jars, manipulate the spoon or knife to remove the peanut butter and jelly and to spread them on the bread?
- Are stability devices, such as non-slip matting under the plastic cutting board, necessary?
- Are sequence prompts necessary? Verbal prompts might be: "The bread is in the package. We need two slices for the sandwich. How do we get what we need out of the package? What do we do with the bread now? Here is the peanut butter jar. What comes next?"

Product analysis:

- What was accomplished?
- Which skills were practiced and achieved independently? Which needed assistive devices or equipment?
- How many prompts were necessary? What type were they? Is it possible to minimize them during the next meal preparation?

The results: Self-made peanut butter and jelly sandwich, self-esteem boost, independence in self-care activity reinforced.

Performance analysis:

Over the years, special education teachers, therapists and researchers have identified those behaviors that commonly reduce effective performance of life skills. Analysis of such behaviors is ongoing by therapists and educators as their students participate in each school activity. Parents may also engage in this analytic process as they observe their teen's behavior in summer activity. Here's how. Consider to what degree these characteristics may impede life skill performance:

- Lack of initiative: teen seems to need someone else to initiate an activity idea.
- Lack of or delay in planning and sequencing: difficulty with sequencing movements or "think it through" steps to finish an activity.
- Decreased attention, distraction, or daydreaming: teen moves from one task to another without completing the first. Seems distracted while instructions are given and does not follow them completely.
- Difficulty with transitions from activity to activity. Seems agitated or becomes loud before, during or after changes, whether in location, activity or time.
- A tendency to fatigue often or tire easily. Teen lacks enough energy to complete one activity, even if it is a favorite.

> Activities and how they are performed must be evaluated before life skill strategies can be applied effectively.

- Disorder, clutter: items left around, not put away (eg, clothes strewn from attic to basement; sports equipment and parts of games scattered throughout the house).
- Difficulty remaining seated for an activity, squirming or fidgeting.
- Lack of safety awareness or possible consequences

It is important for parents to keep in mind that activity analysis should not be separate from the family's daily routine. Rather, including the teen during such routine family activity as meal preparation, and facilitating participation with minimal prompts, encourages competence and independence. The same principles may be applied to household tasks such as laundry, outside chores or general household cleaning. Include the teen in one or more activities that are components of the overall job. After analyzing three activities—one in the kitchen, one in the bedroom or family room and one outside in the yard—parents will become adept at using the Materials, Process and Product analysis on the fly to apply techniques that will promote independence in the home.

Activity Synthesis

Synthesis pulls together practical strategies applied to characteristics and behaviors across all life skill domains. As these strategies start to work with the teens, they will experience a sense of accomplishment and independence they can carry with them when vacation is over and the next school year begins.

Suggested Strategies for Bridging the Summer Gap

Once they become practiced in analyzing their teen's activity and performance, parents need strategies that encourage their teen's independence in the home and community. Techniques used daily by teachers and therapists can enhance the teen's ability to focus on and complete functional skills necessary in daily living. Most strategies are common to all domains and may cross over from one to another.

General Strategies:

- Break each activity down to its smallest components. Use pictures, lists, charts and verbal prompts as needed for completion.
- Keep charts and lists simple and uncluttered.
- Reduce the complexity of an activity and the length of time it takes to complete a task.
- Use simple, concrete instructions.
- Remember that young people with

continued on page 34

continued from page 33

memory difficulties may require many verbal or visual repetitions of the steps in an activity.

- Give a "pat on the back" for successful task accomplishment or participation.
- Prepare for transitions. Use a timer set for five minutes or another auditory prompt before a change of activity, preparing the teen for a change such as "When the timer on your watch goes off, we'll get ready to go swimming."
- Provide a sense of external order. Put pictures or written labels on drawers of clothing. Hang like items together in the closet: shirts with shirts, for example, and pants with pants. In the kitchen put pictures or written labels of the contents on cabinets and drawers.
- Plan activities out beforehand, especially those outside the home. Make a trip to the location before an event—say, a birthday pool party—and review the potential dangers.
- Use calendars, charts and lists of planned activities for the day, week or month.
- Reinforce the familiar "STOP, LOOK and LISTEN."
- Pair your child with a responsible friend or relative.
- Emphasize the importance of balancing high-energy activity with sedentary activity: swimming followed by reading or listening to music, nature hikes followed by group discussions, boating followed by board games or group drama sessions.
- Avoid relying on prompts for every component of an activity. Allow your teen time to think it through.
- Use family meetings to assign room jobs, kitchen jobs and general household jobs to all. In this way your teen feels like a part of the team.
- Remember, it's summer! Taking some time out to lie on the grass and daydream is therapeutic (for both parents and teens).

Strategies specific to social/communication skills:

- For teens who tend to avoid eye contact and/or mumble with their head down, verbal reminders, such as "head up, look at my face while talking" or "look at me," will reinforce basic communication skills practiced during the school year.
- Attention-seeking behaviors such as speaking in a loud voice, interrupting and excessive talking may be handled by agreeing in advance on a parent's signal—perhaps an open hand raised to a cheek—whenever the behavior interferes with conversation. In this way, only the parent and teen know the secret signal, eliminating embarrassing verbal corrections or reprimands in front of others.
- Parents are often able to understand their teen's unintelligible speech and may reinforce poor speaking habits. Therapists suggest parents consistently ask the teen to look up, make eye contact and speak slowly.

Strategies specific to self-help/personal care skills:

- Shop for personal care items together. Let teens choose products themselves (within reason).
- Place a colorful plastic container or basket in the bathroom to hold all of your teen's personal grooming items. This helps in maintaining organization, especially if there is more than one teen in the household.
- Support exercises and activities that encourage proper alignment and posture and increase muscle tone, circulation and stimulation. Swimming, gymnastics, simplified yoga, tai chi, modified ballet and modern dance are all possibilities.
- Encourage proper nutrition with guided food shopping, cooking and baking sessions.
- Shop using grocery items pictured or written on 4"x6" cards. (Use coupons or newspaper pictures. The photos of the products shown will exactly match the products on the shelves, insuring successful item selection). Give the teen a collection of six cards or coupons and instructions to go through the aisles to find those items.
- Arrange partner shopping with a sibling, cousin or friend of your teenager. Make sure they are within close proximity to one another and that you are within calling distance.
- Have your teen plan simple meals, such as breakfast tacos or lunch sandwiches, using simple but detailed instructions on 4x6 cards, and set out (non-perishable) ingredients the night before. For complicated dishes, present directions in clear picture or word form, breaking each task down to its smallest component and have the teen complete each component sequentially.
- Remember to work within the normal activity schedule of the family. Incorporate life skills using prompts, and include peers for support. This method is relaxing and satisfying for parents, siblings and teens.

Strategies specific to community activities:

- The key to preparing for independence in community settings is including your teen in planning outings and using the experience as a learning tool. As you run family errands, talk over the purpose of each errand. Review the process needed to complete transactions at the bank, for example, or the post office or the dry cleaners. "What do you think will happen here?" "Why are we visiting the library this afternoon?"
- Review recognition of safety signs as you drive or walk with the family. Point out the STOP, RR (Rail Road), Push/Pull, Women's and Men's bathroom signs and ask your teen what to do at each sign.

...And the livin' is easy

Parents of adolescents may experience difficulty in maintaining age-appropriate independence and in balancing purposeful activity with rest and relaxation during the summer months. Practicing these strategies in everyday summer routines can easily and naturally promote and reinforce independent life skills. Backsliding will be minimized and teens with special needs may actually gain new skills for the coming year. By adapting these suggested techniques and strategies for use in summer's daily routine, parents encourage enthusiasm for independence and build their teen's self-reliance and reinforce self-esteem.

Carolyn O. Cantu , MS, OTR, is a licensed pediatric occupational therapist and educator with thirty-two years of experience who has practiced and taught all over the world. Most recently, she was a pediatric therapist and clinicial educator for the Infant Parent Program, Austin, TX.

The author would like to give special acknowledgement for consultation on this article to:

Diana C. Crighton, OTR, Anne Arundel County Health Department Severna Park, Maryland and the Special Education Staff of Anne Arundel County Public School District Severna Park, MD.

Gemma Milner, OTR, and Elizabeth Danner, Special Educator of the Life Skills Program, Westlake High School, and Ann Jinkins, Director of the Westlake High School Special Education Department, Austin, TX.

Enjoyable Activities and Projects

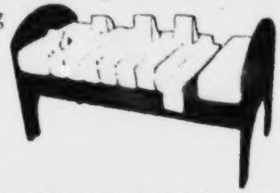
- Summer clubs
- Reading/tutorial programs
- Special Olympics
- Bake sales
- Summer bashes (tee shirts, entertainment, games, arts and crafts)
- Evening street parties
- Community based Routine Family Activities, (shopping, riding buses, banking, errands)
- Volunteer causes such as food banks, state parks, libraries, church landscaping

A way to keep spines straight that's so advanced, a child can do it in their sleep.

Sleep time is one of the most important parts of an adolescent's day. Especially for one with a curving spine. If a child with a curving spine doesn't have night-time support to help keep them straight during their growth spurt, the curving will become a CURVED spine. After that, the only option may be surgery.

With Dreama™, an innovative sleep system from Jenx, a child increases the odds of developing a straighter spine when they hit their growth spurt and into their adult life. By utilizing special foam blocks, Dreama™ adjusts to firmly support a body in any position—supine, prone, and side lying—extending the optimum positioning through 24 hours.

Finally, the straight story on sleeping with a curving spine. From A to Zzzz.



Dreama™. The dream of night-time positioning.

JENX Distributed by BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #22 or visit www.eparent.com/adinfo

Teen & Young Adults

Getting Youth Up To PAR:

Using Participatory Action Research to Increase Self-Determination Skills

by Jessie Sandoval, Tanis Bryan, PhD, and Karen Burstein, PhD

It's not often you find a group of young adults who are willing to spend Saturday mornings working on a university research project. But this is not your typical research project, and these are not your typical young adults. With the involvement of Arizona State University faculty and a strategy called Participatory Action Research (PAR), a group of seven high school and college age students with physical disabilities are studying ways of overcoming the challenges of making the transition to adulthood.

What is PAR?

In PAR the scientific method is used to find solutions to everyday problems. People affected by the problem, not researchers, select the problems to study and collect the data. By using the scientific method participants systematically test strategies to overcome perceived barriers to attaining individual and group goals.

The process begins with participants identifying and defining a pressing problem. They then gather information to determine what is known and what is not known. They select a testing strategy, decide how to measure the effects of the strategy, implement it, record the results and evaluate the data utilizing graphing and statistical procedures. If the problem is solved, they go on to define a new problem. If the problem is not solved, they select another strategy for testing. Finally, participants may decide to take action by letting others know about the results of their research.

According to the National Council on Rehabilitation Education, PAR has become a strategy for effecting change in the field of rehabilitation services. It was used to develop the Reauthorization of the Rehabilitation Act, to document supported employment training job sites, to evaluate programs serving people with severe disabilities, to empower families of children with disabilities and to develop criteria for judging the quality of pediatric care.

Meet the Team

This study to examine perceived barriers to adulthood was conducted by seven high school and college students with physical and/or health and orthopedic impairments. During their sessions, the group learned about the PAR process, testing strategies, data collection, and the need for confidentiality. They learned how the scientific method is used in the social sciences and how the results of studies can impact our daily lives. The members selected a variety of personal goals and devised strategies to achieve them.

Jessie Sandoval is a 20-year-old college sophomore with cerebral palsy majoring in political science.

Casey Walker is a 21-year-old community college student with cerebral palsy.

Jay Dashefsky is a 21-year-old college junior with spina bifida.

Elisha Hilker is a 19-year-old high school student with spina bifida.

Linden Aitken is a 17-year-old high school junior with mitochondrial disease.

Chris Smith is a 19-year-old high school senior who has cerebral palsy.

Nick Luce is a 19- year-old high school student with cerebral palsy. He was a torch bearer in the last Olympics.

Tanis, the project director, was responsible for teaching the PAR process to the team and providing guidance on using it to solve problems. Dave, a young adult with quadriplegia, works for Arizona Bridge to Independent Living (ABIL).

The team completed two group projects. The first dealt with transportation. The team located Donna Powers, Executive Director of the Community Forum and an expert in transportation for people with disabilities in the Phoenix metropolitan area. She came to two meetings via public transportation with power point equipment and lunch packed onto her wheelchair. Following a presentation to the team members and their parents on the rights and responsibilities of persons with disabilities in using public transportation, she brought a bus and a driver to the site so that everyone had a chance to get on board and go for a ride. For some, it was their first time on a bus! Team members learned that there are many ways to access transportation in the Phoenix metropolitan area and how to qualify for these resources, while parents learned that their teenagers could safely use public transportation.

When the team received free tickets from the HoHoKam Baseball Stadium to attend a Chicago Cubs spring training game in Mesa, Arizona, the second team project was born. The group developed the 4-point Baseball Stadium Survey to evaluate the physical accessibility of the stadium. The Survey assesses the parking lot, concession stand, restrooms, ramps, seating and visibility. Each group member independently completed the Survey following the game. The team analyzed their data at the next group meeting. They found that HoHokam Stadium scored very high on parking lot, ramps, seating, and visibility. The stadium staff was helpful, both in the parking lot and in the seating area. After the game, team members were able to park their wheel chairs in a special spot so that they could interact with team members.

There were, however, a number of problems. The concession stand menu was a bit difficult to see and lids were not provided for sodas, making it difficult to carry them back to their seats. The team found it difficult to maneuver their wheelchairs in the restrooms and had problems reaching the bathroom sink. Because the stadium is planning some renovations, the team has drafted a letter

continued on page 38

VISION By VIEWPOINT MOBILITY

The **VISION** Advantage:

- Rear entry design doesn't limit you--park and go anywhere
- Not a bulky full-size van-- VISION can fit in a small garage
- Everybody can ride-- seats up to 7 passengers or 2 wheelchairs
- Conversions available on Chrysler and Ford minivans

Let VISION take you on the road to opportunities.

For a **Free Video** or a
personal demonstration of the **VISION** call
Toll Free 1-877-368-6022

Circle #72 or visit www.eparent.com/adinfo

Camphill Special School
Children's Village
A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- **Pennsylvania Approved Private School**
- **Waldorf Curriculum (Member of AWSNA)**
- **Both Day & Residential Programs Available**

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236
www.BeaverRun.org

Circle #24 or visit www.eparent.com/adinfo

continued from page 37

requesting management to take their experiences into account. That's the action part of participatory action research!

Some Expected—and Unexpected—Results

The group research projects were a natural outgrowth of shared discussions related to personal goals. It is apparent that it is not possible to attend college or work outside the home without transportation, nor is it easy to have social engagements with peers.

Further, it is difficult to participate in ordinary events that most Americans take for granted, like attending a baseball game, if you have to be concerned about getting to a seat or using a restroom. The complicated logistics of ordering, transporting and eating a hot dog and drinking a soda can prevent individuals with disabilities from participating in this ordinary American ritual. Of course friends and family members can assist in many ways, but it is apparent from the team's findings on the Baseball Survey that individuals with disabilities could be more independent and comfortable without engendering significant cost.

Aside from progress in meeting individual and group goals, the PAR process had an impact on the youth with disabilities that is less easily quantified. For one, these youth grew up under the public policy of full inclusion, the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). They lived at home, attended community schools, and most attended general education classrooms. They share the same goals and aspirations as youth who do not have physical disabilities.

Nonetheless, they have had little opportunity to interact with others with disabilities. Everyone benefits from the experience of being able to talk to others like themselves. Group members were much affected by hearing others relate experiences similar to their own. Being able to share these experiences with one another was therapeutic and brought the group closer together.

PAR's emphasis on the scientific process as a means of problem solving is empowering. It helps participants focus on solutions rather than personal frailties. In addition, being responsible for reporting progress toward one's goal to the group is very motivating. More can be learned from this experience than an understanding of the scientific process. Those participating come to care about each other and offer their newfound friends advice, support, empathy and respect. **EP**

BASEBALL STADIUM SURVEY

Please rate the following items.
Name of Stadium ______________________________

A. STADIUM ENTRY AND PARKING LOT

1. The number of handicapped parking spaces was:

Very Inadequate	Somewhat Inadequate	Adequate	Very Adequate	Not Applicable
1	2	3	4	

5. Provisions for entering through the gate were:

Very Inadequate	Somewhat Inadequate	Adequate	Very Adequate	Not Applicable
1	2	3	4	

6. The distance from parking to the stadium was:

Too Far	Not So Far	Pretty Close	Very Close	Not Applicable
1	2	3	4	

B. GETTING AROUND THE STADIUM

7. Maneuvering the ramps were:

Very Difficult	Difficult	Easy	Very Easy	Not Applicable
1	2	3	4	

9. Seating was _______ to find:

Very Difficult	Difficult	Easy	Very Easy	Not Applicable
1	2	3	4	

10. Space around the wheelchair was:

Very Inadequate	Somewhat Adequate	Adequate	Very Adequate	Not Applicable
1	2	3	4	

C. CONCESSION STAND

13. Access to the concession stand from the seat was:

Very Poor	Poor	Good	Very Good	Not Applicable
1	2	3	4	

18. Access to condiments, straws, and napkins was:

Very Poor	Poor	Good	Very Good	Not Applicable
1	2	3	4	

19. Transporting food back to the seat was:

Very Difficult	Difficult	Easy	Very Easy	Not Applicable
1	2	3	4	

D. BATHROOM FACILITIES

24. The access to the facility was:

Very Poor	Poor	Good	Very Good	Not Applicable
1	2	3	4	

25. The room to park a wheelchair was:

Very Inadequate	Somewhat Adequate	Adequate	Very Adequate	Not Applicable
1	2	3	4	

26. The sinks were arranged in such a manner that they were __________ to use:

Very Difficult	Difficult	Easy	Very Easy	Not Applicable
1	2	3	4	

E. PUBLIC TRANSPORTATION

31. Public transportation to the ballpark was:

Very Inadequate	Somewhat Adequate	Adequate	Very Adequate	Not Applicable
1 2		3	4	

32. Do you know if public transportation to the stadium is available?

☐ 1) is available ☐ 2) is NOT available ☐ 3) Don't know

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #48 or visit www.eparent.com/adinfo

ADVERTISEMENT

Universal Newborn Screening

In 1961, Dr. Robert Guthrie of the University of Buffalo developed a laboratory test to detect phenylketonuria (PKU) in newborns. PKU is an inherited metabolic disorder resulting from an enzyme deficiency; if left untreated, it results in profound mental retardation. In 1963 Massachusetts became the first state to mandate screening for PKU, which can be treated by lifelong dietary management and counseling. The National Association for Retarded Children (now The ARC), the Children's Bureau and the Kennedy Foundation were foremost among the organizations that pushed for widespread adoption of the Guthrie test, and by 1966 it was required for all children by all 50 states and the District of Columbia.

Dr. Guthrie and other researchers continued to develop newborn screening (NBS) tests to detect many more disorders, and each state decided what screens would be available for its newborns. Significant disparities resulted; in 1997, in Massachusetts, infants were tested for 10 or more disorders, while Utah's babies were screened for three. Montana and South Dakota each mandated three tests and offered one other by special request only. In the same period, with the introduction of ever-smaller and more powerful microprocessors, technology and equipment became significantly more sophisticated. This permitted testing that had not been feasible before. A process called tandem mass spectrometry (tandem MS, MS/MS) can now run tests for nearly 40 disorders at one time. None are curable, but all are treatable.

In the last two years, many states have expanded their NBS programs. Almost all Pennsylvania hospitals now offer the full spectrum of testing, although the law mandates testing for only six. Massachusetts routinely screens for more than 15 disorders and is running a pilot program offering 30+ tests. Wisconsin has almost tripled availability, from 7 tests to 20. Yet universal NBS still engenders much controversy, and there are many issues to be resolved before consensus can be reached on how the US will move forward.

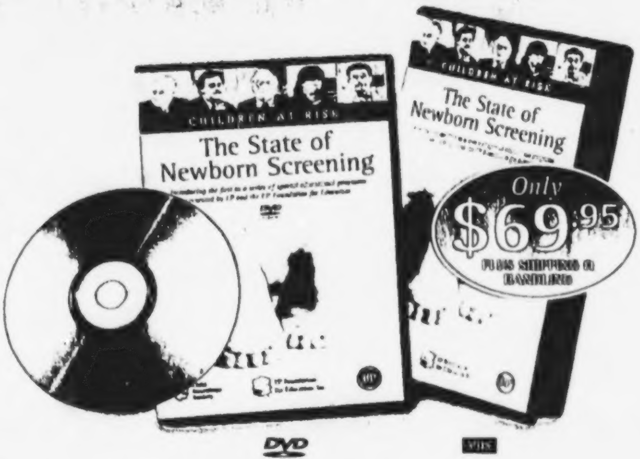
The data tells us that of the four million babies born in the US each year, ten to twelve thousand may have one or more of these detectable...and treatable...disorders

ISSUES: These may be economic, political, professional, sociocultural, religious. Capital spending, training, payment policies, long-term follow-up; insufficient hard financial data; union issues; professional knowledge levels and practice habits; citizen knowledge, and cultural and religious beliefs and practices; insurance, managed care companies, Medicaid, ChIP programs, the uninsured—all these and many more must be part of discussions and resolution.

With the current system, a child born in Louisiana with galactosemia will likely live a life marked by mental retardation and other special health care needs, while similarly affected children born the same day in most of the rest of the country will receive immediate treatment and become productive members of society. The data tell us that of the four million babies born in the US each year, ten to twelve thousand will have one or more of these detectable disorders, an almost-negligible number. The overall cost or benefit to our society, though, will vary wildly from one child to another because of the patchwork of screening availability. We as a nation must find a way to embrace universal NBS and make it routine for all children born in the US. More than that, it is downright wrong not to do so when it has proven its worth time and again!

It is a question of education and awareness. Research shows that the average couple planning to have children does not know anything about existing screening programs, much less the capabilities offered by tandem MS, largely because OB/GYNs, pediatricians, genetic counselors and related professionals are not familiar with universal NBS. The education gap relates to professionals and consumers, rich and poor, people of every race, religion and ethnicity. Few people know much about any of the issues. Worse, among the people who do profess knowledge of NBS and the issues, a good deal of what they "know" is wrong.

The information you need on Newborn Screening is finally available on DVD and video



Children at Risk:

The State of Newborn Screening

is now available on DVD and VHS. Introducing the first in a series of special educational programs presented by EP and the EP Foundation for Education, Inc., a 501(C)3 Not For Profit Corporation.

EP Foundation for Education, Inc. **Child Neurology Society**

Newborn screening can detect up to 39 metabolic disorders from one blood spot. All are treatable when diagnosed at birth, offering the chance for a full and productive life.

Leading medical and scientific professionals are gathered to provide the most current information available. You can view this valuable resource at your convenience and the DVD is indexed so that key topics are easily accessible.

Darryl DeVivo, MD
SIDNEY CARTER PROFESSOR OF NEUROLOGY
COLUMBIA UNIVERSITY

Piero Rinaldo, MD, Ph.D.
DIRECTOR, BIOCHEMICAL GENETICS LABORATORY
MAYO CLINIC

Edwin Naylor, Ph.D.
PRESIDENT
NEOGEN SCREENING, INC.

Joan E. Pellegrino, MD
ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES
UMDNJ-ROBERT WOOD JOHNSON MEDICAL SCHOOL

Paul M. Fernhoff, MD
MEDICAL DIRECTOR
EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #42 or visit www.eparent.com/adinfo

Miracle League Playing Fields

By Maria Tortoreto

Jeremy Ellington, sporting his jersey for the Braves, shows off his swing.

Jeremy Ellington lives for sports. The competitive 16-year-old, donning the jersey for his baseball team, the Braves, hits homeruns and steals bases with confidence. With the crowd cheering him on, Jeremy rounds the bases in his wheelchair every time with a joyful look in his eyes. Playing baseball is a recreational pastime for most Americans, but for Jeremy and the other children in the Miracle League, it is a dream come true.

The Miracle League is an increasingly popular baseball league for children with all ranges of disabilities. Gary Garner, its co-creator, began the league for his daughter Lindsay, now 12, who has muscular dystrophy. Based in Conyers, Georgia, there are over 200 children playing on a dozen teams.

With the help of the local Rotary Club, the parents of players and the Ronald McDonald Foundation, over $750,000 was raised to help build the "McMiracle Field", the first field built especially for the Miracle League which opened in April 2000. Complete with a flat pitching mound and bases, synthetic turf and extra-wide dugouts, this field is ideal for people with disabilities.

Make Dreams come True

Ronardo Scarebrook and his father, Mario, watch the game, anxiously awaiting their turn.

BEST COPY AVAILABLE

PIRATES
RATES
PIRATES
PIRATES
PIRATES
P

The Pirates pose for a team photo with Coach Bubba Hawkins. Since many players in the league have physical limitations, teams are made up of athletes and their buddies who may help them hit, throw or round the bases.

BEST COPY AVAILABLE

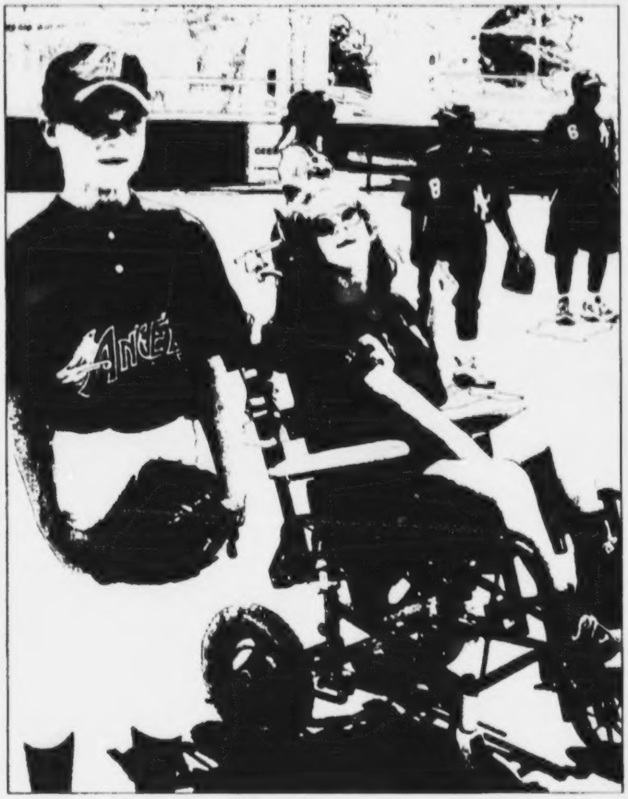
Demetrio Hernandez awaits a hit to the outfield.

Very few rules exist in this unique league. In every inning everyone bats, everyone scores and everyone wins.

Rhonda Moore, whose 8 year-old grandson Demetrio Hernandez was born without arms, had some reservations about signing him up for a sport. "I was afraid of his getting hurt or his feelings getting hurt," she admitted. "But ever since he was little, I've told him 'Don't say you can't. Just try.'" Demetrio, like the rest of his teammates, plays in

continued on page 44

Susie Garner, the league's co-creator, with daughter Lindsay on the McMiracle Field.



Players take a break from the game to smile for the camera.

BEST COPY AVAILABLE

continued from page 43

his own special way, throwing the ball with his feet, because no one is excluded from the Miracle League.

Very few rules exist in this unique league. In every inning everyone bats, everyone scores, and everyone wins. There are only two innings each game, and the last person to bat gets to go around the bases for a homerun. The only competition is players trying to hit the ball harder than last time, or get to first base quicker. Since many of the players have physical limitations making it difficult to play, they have a buddy who helps them hit, throw, and round the bases. Often the buddy will be a family member, but children from the local Little League help out as well.

Since its beginning less than two years ago, the Miracle League has been featured on major broadcast and cable networks as well as appearing in national magazines. With such exposure, interest has stirred all over the country for expansion of the Miracle League. A second field has been constructed in South Carolina, and 34 others across the country are under way. This fall, one will open in Orlando, Florida and will be featured at the World Congress on Disabilities being held there this October. By the end of 2003, the league hopes to have about 100 fields across the nation.

"We didn't realize the need was as great as it is," said Garner, who owns a small electrical contracting company outside of Atlanta and invests his free time in serving as director of the Miracle League. "What we realized was that (most) handicapped kids did not have anything available to them as far as ongoing athletic activities."

"Our kids are the ones who don't get invited to the birthday parties, and they're not the ones who other kids invite to come over to their house after church on Sundays," adds Garner. "That makes this activity that much more important to them."

Jeremy's mother, Debra Carter, sees more positives for the players than simply self-confidence. It's a networking system; the children make friends while the parents talk about new research and doctors for their children, all the while doing something great for the community.

As Jeremy said to Debra after a recent game, "It's awesome, mom!" EP

New York School Renamed for Mickey Mantle

June of 2002 marked the beginning of a new identity for PS 811, an Upper West Side school for disabled children located at 466 West End Ave in NY. The school was renamed the "Mickey Mantle School" during a ceremoney that included the revealing of a bronze plaque of the baseball hero.

Principal Philip Santise explained that both the students and faculty "are proud to be a part of his (Mantle's) legacy." Santise, a Yankee fan native to the Bronx, was active in getting the school named after "the Mick."

Hyperbaric Oxygen Therapy [HBOT] is the breathing of 100% oxygen under increased atmospheric pressure. The effects of HBOT on the organs and tissues of the body are multi faceted.*

South Florida Center for H.O.P.E offers a clean and bright friendly atmosphere, using only state-of-the-art equipment. Our doctors and technicians are trained by a UHMS accredited course and certified in HBOT by the NBDHMT. They come with many years experience in the field of hyperbaric medicine.

* Hyperbaric Medicine Practice
Eric P. Kindwall, M.D.

WE OFFER **H.O.P.E.**
[HYPERBARIC OXYGEN PRODUCING ENVIRONMENT]

CONDITIONS TREATED WITH HBOT
- CEREBRAL PALSY [CP]
- TRAUMATIC BRAIN INJURY
- ANOXIC ISCHEMIC ENCEPHALOPATHY (AIE)
- NEAR DROWNING
- STROKE [CVA]
- MULTIPLE SCLEROSIS [MS]
- NON-HEALING WOUNDS*
- RADIATION INJURY*
- AUTISM

* CURRENTLY APPROVED BY FDA

ANCILLARY SERVICES
- INTEGRATED MANUAL THERAPY
- PHYSICAL THERAPY
- OCCUPATIONAL THERAPY
- SPEECH THERAPY
- BIO RESONANCE THERAPY
- NEURO-BIOFEEDBACK

Dr. Ross Clark, M.D. Medical Director

South Florida Center for H.O.P.E
1898 H West Hillsboro Blvd.
Deerfield Beach, FL 33442
[954] 571-9392 Toll Free: [866] 473-HOPE

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #63 or visit www.eparent.com/adinfo

Birth Injury Litigation

Michael J. Weiss* specializes in the handling of birth injury cases such as cerebral palsy, brachial plexus palsy and other birth trauma. We have been successful for our clients and their families both at trial and in the settlement of such claims.

If you think your child may have been injured at birth or wish to have additional information, please call toll free 1-888-886-7076.

**Certified by the Supreme Court of New Jersey as a Civil Trial Attorney*

The Law Office of Michael J. Weiss 1-888-886-7076

Circle #79 or visit www.eparent.com/adinfo

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at **DISCOUNT PRICES!**

As a service to our customers, we offer **FREE SAMPLES** of disposable youth briefs and pull ups.

Save up to 50%

Call **1 800 777 1111** 24Hrs
WOODBURY PRODUCTS, INC.

Order online at: **www.woodburyproducts.com**

Circle #75 or visit www.eparent.com/adinfo

Connetquot West, Inc.
Health Care Products

Pressure Management
Nutritional/Enteral
Specialty Seating
Bathroom Safety
Personal Care
Incontinence
Ambulatory
Respiratory
Urological
Beds/Lifts
Skin Care
Mobility

This month's
FREE SAMPLE FEATURE:
First Quality Prevail®
Allnites & Protective Underwear
for older children.
Call for Yours!

Next month:
Nutritionals

866-588-3888
Fax: 866-588-3337
711-3 Koehler Avenue • Ronkonkoma
New York • 11779
Email: connetquot@aol.com

Home Delivery! Quality for You. Quality for Life.™

Circle #28 or visit www.eparent.com/adinfo

Positive lifestyles
for people with developmental disabilities.

Residential, vocational and day programs are provided in a rural village setting. Residents enjoy community living, and a lifestyle designed to appreciate their individual characteristics. Respite care is also available.

Martha Lloyd

190 West Main • Troy, PA 16947 • (570) 297-2185, Ext. 268
www.marthalloyd.org • E-mail: information@marthalloyd.org

Circle #51 or visit www.eparent.com/adinfo

EP NEEDS YOUR HELP!

This fall we are creating some exciting new features and expanding others, but we need your input!

More specifically, we want you to aid in identifying products, services and institutions that are working to make a real difference in the lives of children with disabilities.

To start, we want you to tell us about any effective toy, educational software program, play product or learning tool you or a child with a disability has used. There are no boundaries to these nominations save that they must have been purchased within the last year and are being used by a child with a disability.

We ask that you provide only the following information:

- Your name
- Product name
- When bought (month/year)
- Child using it and his/her disability
- Why the product is effective in helping the child
- Do you have photos (yes or no - Please do not send)
- Any additional comment you may want to make.

Secondly, have you had a particularly good vacation or experience with a hotel, resort or bed & breakfast that made it a point to help children with a disability? If so please let us know as soon as possible so we can include it in an upcoming story about the 15 best hospitality sites in the United States.

Here's the list of information we need:

- Your name
- Name of hotel, resort or bed & breakfast
- Contact or manager (if known)
- Location
- Brief description of your experience
- Do you have photos (yes or no - Please do not send)
- Any additional comments you would like to provide

Finally, for our September issue, we are looking for a wonderful teacher in each of the 50 states. These selfless individuals, regular or special education, will be honored in the issue. But the nomination must come from you, the parents of children with disabilities. If you know of such a person, please include the following information in your nomination:

- Your name
- Name of the teacher
- Contact information
- Location
- Brief description of your experience
- Do you have photos (yes or no - Please do not send)
- Any comments you may want to make.

This is a formidable task we are setting, but it can be done with your help!

Replies to any or all of these requests must be made by August 10, 2002, by emailing us directly at epedit@aol.com or by writing to:

EP magazine
Attn: Megan Henninger
65 Route 4 East
River Edge, NJ 07661

Get-A-Round Gait Trainer

Freedom Designs, Inc. is proud to introduce the new Get-A-Round Gait Trainer. The Get-A-Round offers a "fresh new look" to the gait trainer market. Two sizes are available: small and medium. The Get-A-Round boasts multi adjustments for different functional needs, along with many frame and fabric color choices. The Get-A-Round promotes versatility and function with style.

FREEDOM DESIGNS
INCORPORATED®

MULTI-FUNCTIONAL CASTER

NOTE: Caster Fork Swivel Lock
L- Caster Lock
R- Caster Ratchet (One Way Roll)
F- Caster Free Wheel

2241 Madera Rd., Simi Valley, CA 93065 USA • (805) 582-0077 • (800) 331-8551 • Website: www.freedomdesigns.com

BEST COPY AVAILABLE

Circle #35 or visit www.eparent.com/adinfo

Campers covered in body paint pose for a picture along the beach of Lake Powell, Arizona.

Adventure in Self Discovery

Surrounded by the breathtaking canyon vistas of Lake Powell, Arizona, teens and young adults of all abilities enjoy adapted recreation and building self-confidence at Easter Seals of Arizona's Adventure Camp.

by Bridget M. Lyne

Each summer for the past three years, the unique week-long camp hosts 20 participants, ages 13-23 and provides an adventure for mind and body.

"We give campers the opportunity to experiment with relying on themselves," says Mike Tufte, Easter Seals of Arizona's director of adapted recreation and education who is among the 15 staffers who facilitate the camp. "They find out that the only thing holding them back is themselves, or their parents or families not wanting to let them take that step and experience something on their own."

CONTINUED ON PAGE 50

812

NEW IMPROVED
QUICK-MIX FORMULA
DISSOLVES INSTANTLY. NO LUMPING.

DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

For product literature and advice, a free sample and information where **DIAFOODS THICK-IT** may be purchased, **call… (800) 333-0003**.

Free educational material, call… (800) 333-0003.

The booklet **"Dysphagia, A Review For Health Professionals"** discusses causes, evaluation and treatment of dysphagia.

The pamphlet **"Swallowing Problems"** helps patients and caregivers understand and adapt to dysphagia.

©1996 PRECISION FOODS INC
2150 N. 15TH AVENUE
MELROSE PARK, IL 60160
TELEPHONE (708) 216-070
FAX (708) 216-0709

BEST COPY AVAILABLE

Circle #59 or visit www.eparent.com/adinfo

Above: Campers carefully decorate each other with colorful body paint.

Right: Jetskiing and Kayaking are just a few of the many exciting aquatic activities shared by the campers.

continued from 48

Since the only way to reach the remote camp site is by boat, Easter Seals rents a houseboat that has been made wheelchair-accessible to navigate the trip to one of the lake's secluded coves with a sandy beach. The boat serves as the camp's main gathering place, kitchen and dining hall as well as providing sleeping quarters for some campers with special needs such as ventilators. Others pitch tents on the shore.

Each day has a theme that is celebrated in craft projects and meals. Campers take turns helping in the kitchen at least one meal.

Other activities at camp include a variety of sports and aquatic recreation, from swimming and riding wave runners to hiking and fishing. "We bring all the tools that we can think of and adapt each event for whatever the needs are so that everyone can enjoy it," says Mike. Some modifications include outfitting kayaks with seats and back rests for kids who need support, and portable plastic flooring for

southpaw enterprises®
DAYTON, OHIO U.S.A.

Providing Hundreds of Sensory Integration and Development Product Solutions!

Therapists, educators, parents and physicians acknowledge Southpaw as the industry leader in providing high-quality, state-of-the-art and safe Sensory Integration and Developmental products. Our products are made to the strictest standards of quality. We also strive to make our products fun while providing you with the innovative and safe solutions you require for great therapy.

Phone toll free:
1-800-228-1698

Or contact us from our website:
www.southpawenterprises.com

Call for our FREE full line product catalog!

Southpaw Enterprises
P.O. Box 1047
Dayton, OH 45401-1047

Circle #64 or visit www.eparent.com/adinfo

Camp Cuisine

SOPAPILLAS

Ingredients

1 cup flower
1/4 cup buttermilk
1/4 cup water
1 tsp vegetable oil
1 tsp baking powder
1/2 tsp salt

Combine flour, milk, oil, powder and salt in bowl. Mix well. Turn dough out onto a floured surface and roll 1/8 inch thick. Fold dough in half and roll again to same thickness. Cut into three-inch triangles.

Heat 4 cups oil in a large, deep skillet (about 375 degrees). Add triangles, a few at a time, and fry on both sides until golden brown. Remove and drain on paper towels. Sprinkle with powdered sugar and serve. Drizzle honey if desired.

sidewalks—giving campers with mobility challenges easy access around the site. "It's ideal for putting along the beach front to get campers right up to the edge of the water," Mike explains.

Campers also participate in team-building games which demonstrate that they each have a contribution to make. Mike notes that the sense of accomplishment from the entire Camp experience is invaluable. "They find out that everyone has a disability of some kind, and that everyone also has strengths. Here they are in a remote area, where they have to work a bit, doing something exceptional. For a young person with some significant disabilities in his or her life, this is a real confidence boost, you can see it in their eyes and the smile from ear to ear."

To help parents cover the cost of sending their teen to camp, Easter Seals of Arizona provides income-based scholarships and has worked to get the camp covered under state-funded respite. EP

For more information about Easter Seals of Arizona, check out their Web site: http://www.azseals.org

With the Creepster Crawler, You Can Watch Your Child Crawl for the First Time!

Children lacking head control, the ability to roll over or belly crawl have gained mobility with the ***Creepster Crawler.*** Using this light, innovative device, hundreds of children around the world are crawling, working more productively with their therapists, and gaining a head start to more advanced mobility in the future.

The ***Creepster Crawler*** is an ideal solution for youngsters with debilitating conditions such as ☐ Spina Bifida ☐ Down Syndrome ☐ Cerebral Palsy ☐ TBI, and ☐ developmental delays. Children with tracheostomies and G-Tubes also are successful users of the ***Creepster Crawler.***

The ***Creepster Crawler***'s frame has a padded platform that can support a parent or therapist from above, making it easier to work with the child on weight-bearing, weight-shifting, reaching and creeping. Front shoulder, chest and rear straps can be adjusted for individual fit.

Please visit our Worldwide Web site at www.redbarn-enter.com for additional details and a video demonstration of the ***Creepster Crawler.***

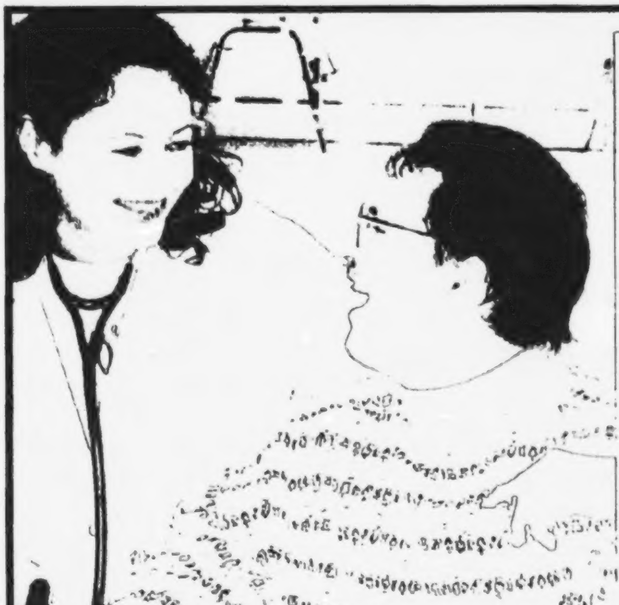
Call for a Brochure!
1-800-577-1317
Fax:1-602-242-9211
or email us at info@red-enter.com

RedBarn ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.redbarn-enter.com**

CAUTION: Children should not be left unattended in the Creepster Crawler.

Circle #60 or visit www.eparent.com/adinfo



The Many Faces of Matheny.

A lifetime of caring for people with developmental disabilities.

Award-winning programs for children and adults in medicine and education

- Residential
- Outpatient
- Home Health

As an affiliate of major universities and hospitals, Matheny shares its expertise with the medical community.

MATHENY
School and Hospital
Main Street, P.O. Box 339
Peapack, NJ 07977
908.234.0011
www.matheny.org

Circle #52 or visit www.eparent.com/adinfo

HYPERBARIC OXYGEN THERAPY

Hyperbaric Oxygen Therapy (HBOT, HBO, HBO2) uses a special chamber to allow a person to breathe 100 percent pure oxygen while the pressure in the chamber is higher than one atmosphere. HBOT first received approval from the FDA as a treatment for divers' decompression sickness (the bends). Additional indications for HBOT use can be divided into two categories circulatory conditions and wound repair.

CIRCULATORY & WOUND HEALING

Providing pure oxygen at higher-than-normal pressure counteracts the effects of these conditions. In carbon monoxide poisoning, decompression sickness and smoke inhalation, the added oxygen returns the mix of blood gases to normal; whereas in an air or gas embolism the higher pressure bursts the bubble obstructing a blood vessel and normal blood flow is restored.

In wound healing, higher pressure speeds up the oxygenation process, killing bacteria and allowing the wound to heal. Hence, an injury will heal faster at sea level than an identical one at 8000 feet.

TREATING CEREBRAL PALSY (CP)

CP is thought to result from an injury or insult to the brain, prenatally or perinatally, that creates lesions. It is a collection of disorders, not a disease, and the degree of each disorder can vary. Someone with CP is likely to have hypertonia—spasticity—of one or more groups of muscles. The likelihood is high that individuals with CP will have some degree of developmental delay and possibly a seizure disorder such as epilepsy.

There is no cure for CP at this time, only amelioration of symptoms. Among the therapeutic modalities used have been physical, occupational and/or speech therapy, patterning, selective dorsal rhizotomies, intrathecal baclofen pumps, and injections of botulinum toxin A.

Although it is a so-called "off-label" use, CP has been treated with HBOT since the mid-1980s. Anecdotal evidence suggests that HBOT usage results in reduced spasticity, improvement in balance and hypotonia, acceleration of language and cognition, and increased awareness and attention. Thousands of children around the world have received HBOT based on such reports. However, the results of only a few small clinical trials have been published. The most widely known is the "Canadian study;" whose finding are considered interesting but not conclusive.due to flaws in the design of the study.

NEW INFORMATION

Between January 1999 and March 2000, the Division of Child Development at Weill Medical College of Cornell University (Evelyn Lipper, MD, Director; Maureen Packard, MD, principal investigator) studied the effects of 40 one-hour HBOT sessions at 1.5 atmospheres on the motor, cognitive and language skills of 23 young children with moderate to severe CP. The findings are being prepared for publication.

The researchers used standard assessment tools to monitor changes in study participants. Additionally, parents were asked to keep diaries of their child's progress, noting changes in sleep, feeding, toileting, illnesses, mood/energy, movement, play, attention/alertness and language (words or sounds).

RESULTS AND CONCLUSION

The researchers discuss at some length the results over time, including patterns of changes, side effects, and the overall impact of HBOT on children depending on age, symptoms and degree of involvement. They note that some 30 percent of families reported regression after HBOT therapy ended. The researchers conclude that "For some children with moderate to sever CP, there is evidence that HBOT improves motor skills, attention, language and play…The changes observed do not constitute a cure of CP, but do constitute functionally substantial improvement." EP

HBOT

At MIRACLE MOUNTAIN

(located in the beautiful Blue Ridge Mtns. of NC)

Using the Coop method, your average cost for a group session is now **LESS THAN $3000** which includes:

- ☐ **40 sessions (Multiplace Chamber)**
- ☐ **Oxy-Sound Harmonics**
- ☐ **Auto-Quad Patterning**
- ☐ **Essential Oil Therapy training**
- ☐ **Housing (everything but food)**
- ☐ **We can assist with possible free Airline Tickets**

Ph: 336-385-1775

CHECK OUR WEB PAGE AT:
WWW.MIRACLEMOUNTAIN.HOMESTEAD.COM
/COOPERATIVE.HTML

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #81 or visit www.eparent.com/adinfo

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C.
& Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #50 or visit www.eparent.com/adinfo

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD
WCD

World Congress & Exposition on Disabilities

October 3-5, 2002 ◆ Orlando, Florida

EDUCATIONAL SPONSORS
Allergan, Inc.
American Academy for Cerebral Palsy
& Developmental Medicine (AACPDM)
American Academy of Pediatrics
American Association for Active Lifestyles & Fitness (AAALF)
Association of University Centers on Disabilities

Over 200 Conference Sessions

Over 250 Product & Service Providers

Sports & Recreation Activity Center

Employment Pavilion

Assistive Technology Learning Center

Employment Symposium
Sponsor
VR
Florida Department of Education

MEDIA SPONSORS
Active Living magazine
Disabled Dealer of Southeast
EP (Exceptional Parent)
inMotion
New Mobility
PALAESTRA
Paraplegia News
Sports 'N Spokes
Teaching Exceptional Children
Today's Caregiver
We Media

SUPPORTING ORGANIZATIONS
AAMR
America's Athletes with Disabilities
Amputee Coalition of America
Autism Society of Florida
Council for Exceptional Children
Easter Seals
Families of S.M.A.
Family C.A.F.E.
Family Voices
Florida Alliance for Assistive Service
and Technology, Inc. (FAAST)
Florida Children's Forum/Central Directory
Florida Institute for Family Involvement (FIFI)
Muscular Dystrophy Family Foundation
National Family Caregivers Association
National Multiple Sclerosis Society
National Perinatal Association
RESPECT of Florida
Southeast Disability & Business Technical
Assistance Center
Special Olympics
Spina Bifida Association of America
TASH
UCP
United Parents' Syndicate on Disabilities

818

BEST COPY AVAILABLE

(877) 923-3976 x832 ◆ wcdinfo@wcdexpo.com ◆ www.wcdexpo.com

HAB H.A. BRUNO, LLC
EP Exceptional Parent
sigma-tau PHARMACEUTICALS, INC.
EP Foundation for Education, Inc.

Circle #76 or visit www.eparent.com/adinfo

Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—October 3 - 5, 2002
LOCATION:
Orange County Convention Center—Orlando, Florida

A UNIQUE GATHERING—A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract **physicians • families • direct support professionals • people with disabilities • allied health care professionals • educators • adapted physical education specialists.**

TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.

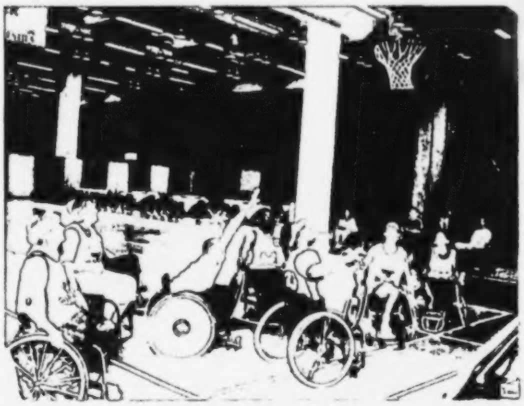
SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more, hosted by America's Athletes with Disabilities.

EMPLOYMENT SYMPOSIUM PAVILION: Human resource managers will discuss career opportunities, sponsored by the Florida Department of Education, Division of Vocational Rehabilitation Services (VRS) and McDonald's Corporation.

ASSISTIVE TECHNOLOGY LEARNING CENTER: Produced by FAAST. Computer Stations designed for hands-on education and fun.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.



CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment.

- All WCD attendees can experience discussions by internationally renowned experts specializing in neurology, orthopedics, pediatrics, internal medicine, family medicine, physical medicine, epidemiology, DDS, movement disorders, mitochondrial and metabolic disorders, neonatology, seizure disorders, autism, and other disabilities and chronic conditions as well as general practitioners.
- CME and CEU accreditation will be provided through approved accreditation institutions.
- Hear parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.
- An Employment Symposium produced in conjunction with the VRS will offer sessions for people with disabilities, their families and employers.
- Learn from special education professionals what is going on in classroom environments.
- Participate in adapted physical education activities and seminars.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

WORLD CONGRESS & EXPOSITION ON DISABILITIES ANNOUNCES STELLAR KEYNOTE LINE-UP

The World Congress & Exposition on Disabilities (WCD) announces its Keynote Speakers for the Third Annual event, taking place October 3-5, 2002 in its new location the Orange County Convention Center in Orlando, Florida. Four industry leaders from the educational, medical, business and military sectors are scheduled to speak. Governor Jeb Bush is an intended special guest speaker on Friday, October 4th at 5:30 p.m. The WCD (www.wcdexpo.com) is a comprehensive forum that educates, informs and provides a useful exchange of ideas between persons with disabilities and special needs, their families, health-care professionals and educators

"We're thrilled about the 2002 Keynote Address Program. Our attendees will have the rare opportunity to be exposed to and educated by true visionaries in their respected fields. We anticipate an excellent response to this year's speakers," said Steve Gross, Vice President of WCD.

Robert H. Pasternack, of the U.S. Department of Education, will kick off the WCD Keynote program on Thursday, October 3rd at 10:00 a.m. Mr. Pasternack is the Assistant Secretary for Special Education and Rehabilitative Services and serves as principal advisor to the U.S. Secretary of Education on these matters. He also has a lifelong personal experience with people with disabilities, as the legal guardian for nearly 20 years for his brother, who was born with Down syndrome.

On Thursday, October 3rd at 5:15 p.m., Jeff Taylor, Founder and Chairman of Monster and Global Director, Interactive of TMP will present his speech. Mr. Taylor is recognized as an innovator and a visionary in both the Internet and career industries. Through Mr. Taylor's guidance and leadership, Monster catapulted to the number one position in the online career industry, currently serving over 10 million job seekers each month, and has reinvented the way in which the world looks for employment.

Francis S. Collins, M.D., Ph.D., a Physician-Geneticist for the National Human Genome Research Institute (NHGRI), part of the National Institutes of Health, will deliver a Keynote on Friday, October 4th at 10:00 a.m. Dr. Collins oversees a complex multi-disciplinary project aimed at mapping and sequencing the entire human DNA, and determining aspects of its function. This is considered one of the most important scientific projects of our time.

The final Keynote address will be presented by General James L. Jones, 32nd Commandant of the Marine Corps and his wife, Mrs. Diane Jones on Saturday, October 5th at 9:00 a.m. General Jones illustrious career has spanned over 35 years of serving his country including active duty in Vietnam, Japan, Northern Iraq, Turkey, Germany, Bosnia, and Macedonia. He was promoted to General on June 30, 1991 and assumed his current post on July 1, 1999. The General and Mrs. Jones are active members of the U.S. Armed Forces Exceptional Family Member Program. This program provides assistance to family members of service personnel who have special needs.

Mrs. Jones has been a lifelong advocate for individuals with disabilities, beginning thirty-one years ago with the birth of a daughter with Fragile-X-Syndrome. Combining this role with being a strong supporter of military families, she has made significant contributions to both the Marine Corps family and to people with disabilities.

With a Master's Degree in Special

Education, Mrs. Jones' career path has included being a teacher and administrator in special education, and a Governor's appointee to the California State Council on Developmental Disabilities. As First Lady of the Marine Corps, she has been instrumental in improving the quality of life for those Marines with family members in the Exceptional Family Member Program by fostering a Committee for Persons with Disabilities on every major Marine base, as well as services and partnerships that have resulted in improved accessibility, childcare, respite care and recreational options.

In addition to the Keynote Addresses, the WCD will present an intensive three-day multi-disciplinary conference program that includes more than 200 educational sessions. The exhibit floor will feature more than 250 companies showcasing the latest products and services including pharmaceutical, assistive technology, automotive, mobility, durable medical equipment, personal care, insurance, computer, nutrition and many other industries. For more information on the WCD, visit www.wcdexpo.com or call 1-877-WCD-EXPO.

EXHIBITORS

AAMR
Accessibility Services, Inc.
A.C.F. Environmental
Acorn Stairlifts Inc.
Active Living Magazine
Advanced Respiratory
Advantage Vans
  of Central Florida
Allergan, Inc.
Alternatives for Special Kids
American Academy
  for Cerebral Palsy &
  Developmental Medicine
  (AACPDM)
American Association for
  Active Lifestyles &
  Fitness (AAALF)
America's Athletes with
Disabilities
Amputee Coalition of America
Anew International
Angelman Syndrome
  Foundation
Anne Carlsen Center
  for Children
Aquatic Access Inc.
Aurora Ministries
Autism Society of Florida
Barrier Free Lifts
Best Bath Systems
Betacom Corporation
Beyond Adversity TV
BeyondHearingAids.com
Bodypoint Designs Inc.
Body Sense
Bunni-Steps Design
Cambrooke Foods
Canine Companions
  for Independence
Challenge Publications
Child Neurology Society
Children's Medical Services
Cloister Creek
Columbia Medical
Communication
  Access Network
Communicating
  Partners Center
Concord
Continental Press/
  Seeding Publication
Convaid Inc.
Council for
  Exceptional Children

Crotched Mountain
Custom Mobility, Inc.
David Mandt & Associates
DBH Attachments Inc.
Defense Threat
  Reduction Agency
Department of
  Veterans Affairs
Department of Defense
  Dependents Schools
Dietary Specialties
Disabled Dealer Magazine
Dolphin Human Therapy
Downi Creations, Inc.
Driving Aids
  Development Corp.
Drymids
Dystonia Medical
  Research Foundation
Easter Seals
Economic Mobility
Effective Communication
  Solutions, Inc.
El Dorado
Emergency Caller Systems/Peat
English Avenue Industries
EP (Exceptional Parent)
EP Foundation for Education,
Inc.
Epilepsy Foundation
Euromed Rehabilitation Center
Families of S.M.A.
Family Voices
Federal Medicare Agency
Flaghouse Inc.
Florida ADA
  Leadership Network
Florida Alliance for
  Assistive Service and
  Technology, Inc. (FAAST)
Florida Children's
  Forum/Central Directory
Florida Independent
  Living Council
Florida Institute for
  Family Involvement (FIFI)
Florida Spinal Cord
  Injury Resource Center
Ford Mobility
  Motoring Program
Freedom Concepts

Gabby's
Genzyme
Guldmann Inc.
HealthSouth
Heartspring School
Hewlett Packard
Hoveround Corp.
inMotion Magazine
Invacare
International
  Broadcasting Bureau
Island Dolphin care, Inc.
JayJo Books
Judge Rotenberg
  Educational Center
KayJae Manufacturing Co., Inc.
Learning Strategies, Inc.
Magitek.com, LLC
McDonald's Corporation
Merrill Lynch & Co., Inc.
Metroplex Voice
  Computing Inc.
Mind Wing Concepts, Inc.
Mulholland Positioning
  Systems, Inc.
Muscular Dystrophy
  Family Foundation
MyMedMart, Inc.
National Disability
  Sports Alliance
National Family
  Caregivers Association
National Institutes of Health
National Multiple
  Sclerosis Society
National Perinatal Association
Newhope Generation
New Mobility Magazine
NISH
Ocean Hyperbaric Neurologic
  Center
Oxy-Health Corporation
PALAESTRA
Pathways Development
  Group, Inc.
Perkin Elmer Life Sciences
Possibilities Foundation, Inc.
Prentke Romich Company
Pride Mobility Products Corp.
Rare Disease Therapeutics
Remedia Publications

RESPECT of Florida
Ricon
Rifton Equipment
Ross Laboratories
Sammons Preston
Scooter Lift Mfg Co.
Search Beyond Adventures
Shire US Inc.
SHS NORTH AMERICA
Sigma Tau Pharmaceuticals, Inc.
Social Security Administration
  Office of Disability
SourceAbility
Southeast Disability
  and Business Technical
  Assistance Center
Southpaw Enterprises, Inc.
Special Olympics
Spina Bifida Association
  of America
Sunrise Medical
Super Duper Publications
SureHands Lift &
  Care Systems
TASH
Teaching Exceptional Children
Texas Neuro Rehab Center
The Autism
  Recovery Foundation
The Center for Discovery
The Disability Resource
The Hali Project
The Liberty Motor Co.
The National
  Neurofibromatosis
  Foundation, Inc.
Theradapt
Today's Caregiver Magazine
UCP (United Cerebral Palsy)
United Parents' Syndicate
  on Disabilities
Universal Motion
U.S. Customs Service
U.S. Department of Justice
U.S. Disabled Athletes Fund
Vail Products, Inc.
Vision For Life
Volkswagen of America
W.B. Saunders/Mosby/Churchill
WALMART
We Media
WE MOVE
Wheelchair Getaways

Exhibitors at press time

For complete details, visit our website at www.wcdexpo.com.
For a free conference brochure, call: (877) 923-3976 x832 or email: wcdinfo@wcdexpo.com

Wheelchair Getaways®

The Leader In Accessible Van Rentals

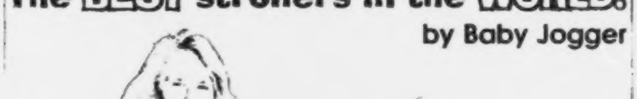
- Long/short term rentals
- 24-hr emergency assistance
- Pick-up and delivery
- Full size and mini vans

We Deliver Accessibility!

Nationwide Rental Information:
(800) 642-2042
www.wheelchairgetaways.com

Circle #74 or visit www.eparent.com/adinfo

The BEST strollers in the WORLD!
by Baby Jogger


Our Special Needs strollers are lightweight, easy to fold, and a joy to push...
www.babyjog

Circle #67 or visit www.eparent.com/adinfo

Appeals Court Allows Patients to Sue States

In an important victory for children with disabilities and other Medicaid patients, two federal appeals courts have ruled that people may sue state officials not providing benefits promised under the federal Medicaid law.

Previously, states have reduced or eliminated services mandated by Congress while claiming exemption from legal action under the doctrine of sovereign immunity. However, in decisions made this past May, the Court of Appeals for the Fourth Circuit in Richmond, VA, and the Sixth Circuit in Cincinnati, OH, rejected these arguments. This opened doors for some of the nation's 40 million Medicaid recipients who may now sue in order to enforce provisions of federal laws not implemented by individual states. The two appeals cover the states of Virginia, North Carolina, South Carolina, Michigan, Ohio, Maryland, West Virginia, Kentucky and Tennessee.

State officials claimed support from recent Supreme Court decisions that sided with states fighting against congressional mandates. However, as the Richmond court ruled, "a state officer acting in violation of federal law loses the cloak of state immunity." Writing for the Richmond court, Judge Paul V. Niemeyer said that since (North Carolina) elected to participate in the federal Medicaid program, (it is therefore bound) by the requirements of the (federal) Medicaid Act. Exception for any state, Niemeyer stated, lay only "if the state declined federal funds and operated a state program for medical assistance using its own standard, or to decline to operate such a program at all."

Other federal circuit courts are expected to hand down similar decisions as cases begin to reach them. However, what these rulings will mean in the short term is unclear. State officials in both instances indicated they would evaluate whether an appeal to the Supreme Court would overturn these rulings. In the recent past, the Supreme Court has sided with the states on many issues.

New Publication on Parentally Placed Students

The Urban Special Education Leadership Collaborative and the IDEA Local Implementation by Local Administrators (ILIAD) Partnership announce a new publication intended to provide an overview of IDEA and relevant case law pertaining to parentally-placed students with disabilities in private schools. This may be obtained free of charge by visiting their website http://www.ideapractices.org/resources/detail.php?id=22082 and by contacting ILIAD at (877) 232-4332 or (866) 915-5000 (Toll free TTY).

Jewelry Promotes Equality

Audrey Lewis, founder of Created Equal, Inc. and a mother of a child with Spinal Muscular Atrophy has designed a new way of honoring friends and family living with a diisability. Her line of family pins features children, men and women (in wheelchairs or standing) and angels formed from sterling silver. A portion of each sale will be donated to the Greensboro Justice Fund and Families of Spinal Muscular Atrophy (S.M.A.) For more information on Created Equal, Inc and their jewelry call (800) 304-8129, write to P.O. Box 6212, Libertyville, IL 60048, email CreateEqual@aol.com, or visit their website: http://www.created-equal.com.

NDSS Launches Web site for Teens

Launched in May, Club NDSS is the first interactive online community for teens and adults with Down syndrome and other developmental disabilities. The site provides message boards, photos and stories about people with Down syndrome as well as Internet and computer training. Upcoming features include a "my web page" feature and moderated chats. Access the site by visiting http://www.ClubNDSS.org.

CALENDAR OF EVENTS

8/23-25 National Down syndrome Congress 2002 Annual Conference

Join the NDSC in Denver, CO for an array of presenters including professionals, self-advocates and parents with professional expertise. Separate conferences for teenagers and adults with Down syndrome and for siblings ages 12 through high school will also be held. For more information contact the NDSC by phone (800.232.6372), E-mail (info@ndsccenter.org) or by visiting http://www.ndsccenter.org.

9/11-14 American Academy for Cerebral Palsy and Developmental Medicine 56th Annual Meeting

For more information on the 2002 New Orleans meeting contact the AACPDM by phone (847.698.1635), fax (847.823.0536), E-mail (woppenhe@ucla.edu) or by visiting http://www.aacpdm.org.

10/26 Center for Development of Human Services 6th Annual Great Beginnings Conference

Held in Marlborough Massachusetts, this year's focus is Child-Directed Learning. Presentations and workshops cover language experiences, prevention of reading difficulties, challenging behavior, family-centered OT/PT, Autism and culturally responsive practice.
To obtain more information contact Debi Lang at (508)473-3422 x305, dlang@cdhsgroup.org or visit http://www.hsmc.org.

WenzeliteRehab

Providers of
Pediatric
Rehab
Equipment

SEATING SYSTEMS
BATHING CHAIRS
STROLLERS
STANDERS
WALKERS

CALL US AT
718-768-8002 / (800) 706-9255
For information about our
FREE EVALUATION PROGRAM

www.wenzelite.com • e-mail: wenzelite@aol.com

Circle #73 or visit www.eparent.com/adinfo

Special Care for
Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #65 or visit www.eparent.com/adinfo

For Further Reading...

by Megan Henninger

Looking for further information on transition planning? The following titles represent a cross section of books available on this topic. To access these and other titles contact the EP Library online (http://www.eplibrary.com), by fax (201-947-9376) or by calling (800) 535-1910.

THE ROAD Ahead

The Road Ahead: Transition to Adult Life for Persons with Disabilities
EDITED BY KEITH STOREY, PAUL BATES & DAWN HUNTER
Training Resource Network, Inc.
Item Code: PE6963LD Price: $38.95

Storey, Bates and Hunter create a general resource for all disabilities with this book. Each chapter, contributed by various experts in the field of special education, begins with a list of questions that will be answered. To illustrate the ideas being expressed diagrams and tables are included as well as a "Window to the World" case study that applies the strategies outlined in the chapter. Chapter topics include person-centered transition planning, career development, employment, social life skills and interaction, supported living and post-secondary education. Connecting these chapters is the fundamental philosophy that planning for a person with disabilities should include the person in the decision making process. Appropriate for parents, teachers, social workers, employers, IEP team members and other professionals involved with development of a person with disabilities, the book contains references at the end of each chapter and an appendix of helpful organizations.

Adaptivemall.com™
Shop On-line!

Tim's daughter Carrie.. a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.
Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston
Copyright 2001 Bergeron Health Care

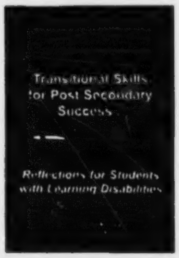
Circle #21 or visit www.eparent.com/adinfo

We Like Making Kids Happy ...

Send For Free Catalog

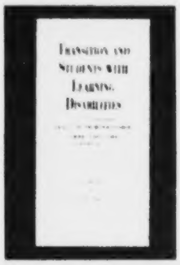
equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094
E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #33 or visit www.eparent.com/adinfo


Transitional Skills for Post Secondary Success
Reflections for Students with Learning Disabilities

Transition Skills for Post Secondary Success: Reflections for Students with Learning Disabilities
EDITED BY TERESA ALLISSA CITRO
Learning Disabilities Association of Massachusetts
Item Code: LD7110LD Price: $24.99

Editor Citro has compiled a practical guide to the transition process that provides advocacy tips for parents and professionals coupled with study tips for teens. The first chapter explains learning disabilities while subsequent chapters furnish information on such topics as standardized tests, choosing a major, financial planning, college hunting, visiting and interviewing at prospective schools as well as explaining resources available in college. Information on testing accommodations, technological aids, an advocacy checklist for parents, a self-awareness checklist for teens, information from the US Department of Education as well as chapter references are included in the back of the book.



Transition and Students with Learning Disabilities: Facilitating the Movement from School to Adult Life
EDITED BY JAMES R. PATTON & GINGER BLALOCK • Pro-Ed Inc.
Item Code: TRN2463GN
Price: $32.95

Designed to give the professional educator a comprehensive overview of transition planning, the book addresses student participation, family involvement, early planning, the importance of cultural factors and a comprehensive overview of transition planning. Chapters discuss the current state of transition planning, barriers to success that exist and possible reform of transition planning legislation, self-determination and life skills, vocational education and rehabilitation, higher education, community transition teams and transition plan assessment. The appendix includes the position statement of the Division on Career Development and Transition of the Council for Exceptional Children. References for further reading can be found at the end of the book.

Coming Soon!

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

HYPERBARIC OXYGENATION FOR THE COMATOSE CHILD

There is some hope for the comatose child suffering from severe brain injuries, cerebral palsy, or anoxic encephalopathy. Children with Glasgow Coma scales from 3-5 present tremendous financial and emotional burdens, since these little ones may live for many years. When considering care of tracheotomy, gastric tube for feeding, physical therapy, occupational therapy, speech therapy, nursing care, recurrent hospitalizations, medications, vans, and modifications to the home, expenditures may represent multi-million dollars.

Intensive hyperbaric oxygenation is no miracle, but it provides some hope. In certain instances the child is able to communicate verbally, by computer or word board. Eighty percent have the G-tube removed and seventy percent have the tracheotomies closed. Frequently, bowels become normal and nutrition is re-established. Routine monthly medications are reduced and hospitalizations are markedly decreased. Although few children will return fully to society, substantial improvements will give them a better quality of life in addition to a ninety percent reduction in overall costs.

For more information on hyperbaric oxygenation therapy and life planning, call the Ocean Hyperbaric Neurologic Center at (800) 552-0255.

Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child..

by R. A. Neubauer, M.D.

Dr. Neubauer's new book is a complete guide written for the professional as well as the caregiver of exceptional children. The book describes the latest information on hyperbaric oxygenation therapy including improved brain function as visualized through functional imaging. Clinical and scientific data along with references are included.

Call 1-800-552-0255 to order.

(800) 552-0255
• *Call for free video & information*

For more information, visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

EP neither endorses nor denies the effectiveness of this therapy. For Editor-in-Chief statement see our Contents page.

Circle #58 or visit www.eparent.com/adinfo

Conquering the Jargon Jungle

Technology terms a parent needs to know

by Sheryl Burgstahler, PhD

It doesn't take much "tech talk" to feel bombarded with technical jargon—intranet, middleware, hypertext, multi-media… Sometimes it is hard to sort out important terms from technical trivia.

I suggest advocating for technology that is accessible for all of the students in our schools. A few tech terms that are important for parents of young people with disabilities to understand in order to advocate for a more accessible world are assistive technology, adaptive technology, electronic and information technology.

Assistive technology (AT) refers to products that people with disabilities use to gain access to environments and activities where their participation would otherwise be limited. AT can maximize physical or mental functioning and minimize the impact of a disability. Assistive technology can help people perform daily living tasks, communicate with others and gain access to education, employment, community activities and recreation. Examples of AT include communication aids, hearing aids, prostheses, wheelchairs, walkers, van lifts and computer access devices.

Sometimes the term "adaptive technology" is used to mean the same thing as assistive technology; in other cases, it refers to a more narrow range of products that provide computer-access, such as speech input devices and alternative keyboards.

Electronic and information technology includes a broad range of products used to acquire, store, manipulate, and transmit information. These technologies include computers, software, Web sites, telephones, science lab equipment, CDs, videotapes, photocopiers, fax machines and calculators.

Universal design is defined by the Center for Universal Design at North Carolina State University as "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design."

To support this idea, the Center established a set of principles to provide guidance in the design of environments, communications and products. These principles embrace the idea that the design accommodates a wide range of individual preferences and abilities; communicates necessary information effectively, regardless of environmental conditions or the sensory abilities of the users; can be used efficiently and comfortably, and with a minimum of fatigue; is an appropriate size; and can be used by people with a wide variety of body sizes, postures or mobility skills.

The concept of universal design can be applied to all instructional activities as well as facility and technology design. For example, the manager of a computer lab is applying universal design when she makes adjustable desks and tables available in anticipation of students for whom the standard table height is not appropriate, perhaps because they are very small or large in stature or use a wheelchair. A teacher is applying universal design when he provides content in a variety of ways to address the needs of auditory learners, tactile learners, individuals who are blind or cannot move their hands and learners with other types of learning styles, abilities and disabilities in his classroom.

Universal design principles applied to electronic and information technology creates products that are more usable by everyone. By considering the needs of people with disabilities in the process they create "accessible" electronic and information technology. These products minimize the need for AT and are compatible with existing AT products.

The following examples demonstrate the benefits of accessible electronic and information technology:

- An accessible videotape has captioning available for individuals who are deaf and audio description available for those who are blind.
- Accessible instructional software

Dr. Sheryl Burgstahler is the director of the DO-IT (Disabilities, Opportunities, Internetworking, and Technology) program. DO-IT is funded by the US Dept. of Education, the State of Washington and many other organizations. DO-IT serves to empower young people with disabilities as they transition to college and careers through the use of computers, assistive technology and the Internet. "Tech Talk" is designed to address practical ways of integrating technology into educational, work and home environments. Dr. Burgstahler will also answer readers questions through this column. Please send correspondence to: Dr. Burgstahler, University of Washington, Box 354842 Seattle, WA 98195; fax: (206) 221-4171; e-mail:sherylb@u.washington.edu.

allows students with disabilities to participate side-by-side with their classmates as they complete assignments and engage in simulations and tutorials. It is compatible with speech output systems used by students who are blind and alternative keyboards used by those who cannot use their hands; and includes visual content alternatives for auditory output so that students who are deaf can participate fully.

- The features of an accessible telephone are usable by people who have mobility, visual and hearing impairments, perhaps in concert with AT.
- Accessible Web pages allow students who are blind to access all of the content at the site using their speech output systems.

Just as ramps installed for wheelchair users also benefit those who are pushing delivery carts or baby strollers, accessible electronic and information technology benefits a wide range of individuals as well. For example, captioning on videotapes can benefit individuals whose first language is not English and individuals who are learning to read.

Access to electronic and information technology has the potential to promote academic and career success for students with disabilities. However, the electronic and information technology that they need to access must be compatible with the AT they use. Also, the facilities, information resources and instruction must be accessible to them in order to gain the full benefits of technology. For example, consider the case where a student who is blind is provided with speech output technology as part of the IEP (Individualized Education Plan) process. This system allows the student to access all of the

continued on page 64

Special Bikes for Special People

2000

A wide choice of
bikes, colors and
adaptive equipment
for people with
special needs.

Haverich

165 Martell Court, Keene, NH 03431
Tel: 603-358-0438 • Fax: 603-358-0453
www.haverich.com

Circle #40 or visit www.eparent.com/adinfo

The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW

- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made In U.S.A.

Circle #37 or visit www.eparent.com/adinfo

continued from page 63

text presented on the computer screen. So far so good. Next, imagine that this student goes to the computer lab to do an Internet-based assignment. She uses her speech output system with the Web site. However, her system cannot read the graphics and they are not presented with text alternatives. Providing text alternatives to describe graphic images is not a difficult thing to do; but unless the Web developer is thinking in terms of universal design it is unlikely he will consider including it.

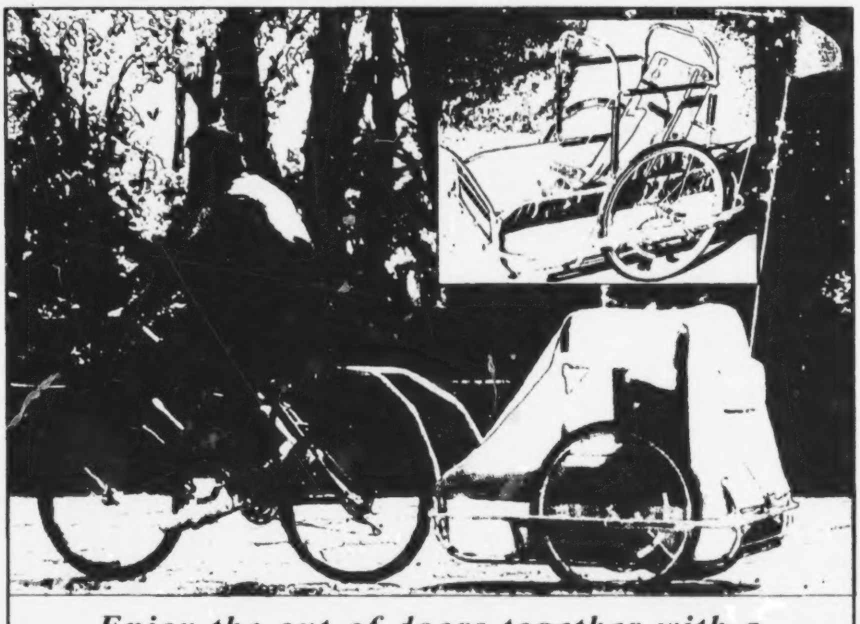
Considering accessible electronic and information technology and universal design of computing environments requires a proactive approach. It requires thinking beyond the needs of an individual child and designing and purchasing accessible products and facilities in anticipation of participants with diverse characteristics. This is a paradigm shift. Currently, many school decision-makers consider access issues only once a specific student with a disability is enrolled. When I visit computer labs that are obviously inaccessible to many students with disabilities, the most common explanation I get from the lab manager is, "We don't have any students with disabilities right now." I then suggest that being both proactive and reactive may be the best solution. Having a few adjustable tables, creating wide aisles, offering track balls as well as mice, providing wrist rests, placing handouts where they can be reached from a seated position and assuring that Web sites they use or create can be accessed using a speech synthesizer are all examples of how they might proactively address accessibility by employing universal design principles.

Putting ideas into action

How can parents and educational professionals put all of this together to state what we should be advocating for in our schools? Here's one way to say it: We want our schools to purchase and use accessible electronic and information technology and apply universal design principles in the creation of its facilities and programs. There should also be an efficient system in place to address the assistive technology needs of specific students with disabilities as they are needed.

Now we know how to say it. That's a good first step, but building accessible information systems in our schools requires the concerted, persistent effort of parents, policy makers, information technology specialists, assistive technology specialists, teachers, and other decision makers. How can schools get started? A good place to start is with district-wide policy that clearly states a commitment to the purchase and use of accessible products, including electronic and information technology. From this, clear guidelines regarding accessible electronic and information technology can be established. Procedures should ensure that accessibility is considered in all stages of technology planning, purchases and support. Creating accessible information systems requires a close collaboration between those who serve students with disabilities and those who make information technology decisions, purchases, and provide technical support. EP

More information about universal design of instruction, electronic and information technology and computer labs can be found at the DO-IT Web site: http://www.washington.edu/doit/Resources/technology.html and at the Center for Universal Design at North Carolina State University Web site: http://www.design.ncsu.edu/ cud/univ_design/ud.htm



Enjoy the out-of-doors together with a
CycleTote® Bicycle Trailer
Running Stroller
1-800-747-2407 www.cycletote.com
Satisfaction Guarantee/Lifetime Warranty

SPORT CORNER

NDSA

BOCCIA ANYONE?

by Debbie Akins

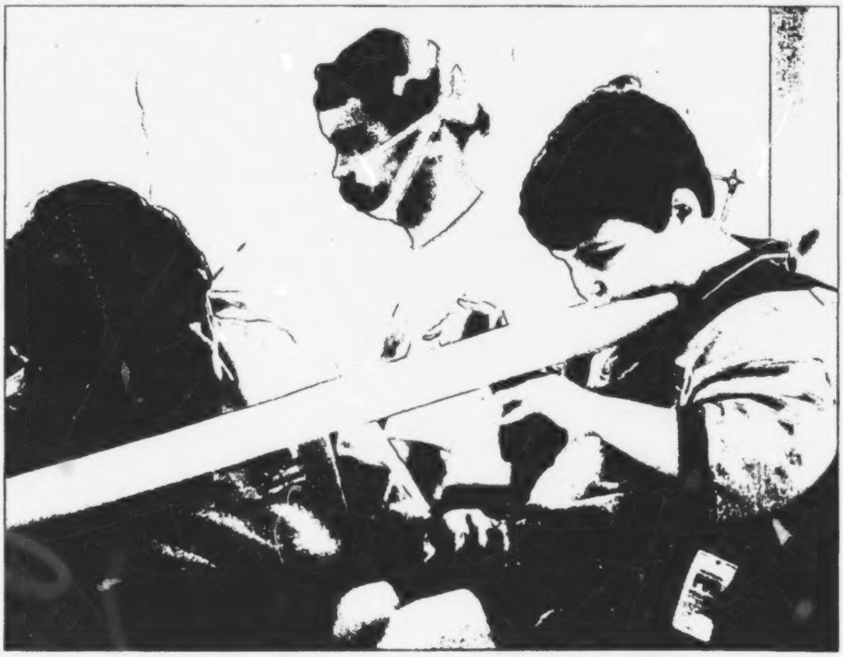
If you are looking for some simple summertime sporting fun, boccia may be just the thing. Specially created for people with disabilities, boccia is similar to lawn bowling. Competitors vie to roll their boccia balls closest to a small white marker or "jack ball." The game can be easily integrated into the classroom or recreation center for those with and without challenges. Children with the most significant limitations who cannot grasp the ball to throw it onto the court are able to play with the use of an assistive device (a ramp or chute) to aid in propelling the ball. Boccia is one of the sports that the National Disability Sports Alliance (NDSA) has adapted for competition.

Boccia requires little equipment and can be set up on any gym-type floor. The boccia court requires an area that is 6 meters wide and 12.5 meters long, about the size of half of a volleyball court (see figure on pg. 83). One set of boccia balls includes six blue balls, six red balls and one white jack ball. Modern boccia balls are made of leather which makes them easier to grasp than the original wood or plastic models. The balls are approximately 3.5 inches in diameter and weigh 275 grams (just over half a pound).

The game can be played in individual competition, where two competitors go head to head, in teams or in pairs. In head to head competition, players alternate throwing out the jack ball to start a round. The first competitor throws out the jack ball and then throws out the first colored ball (red), attempting to get the red ball as close to the jack as possible. The other competitor then throws out the blue colored ball and attempts to get it closer to the jack than the red ball. Order of play is determined by the placement of the balls. A player throws until his or her boccia ball is closer to the jack than the opponent's ball. Play continues until each competitor has all six balls on the court. The score is then calculated by determining which competitor's boccia ball is closest to the jack ball and then counting how many of that competitor's boccia balls are closer to the jack than the nearest ball of the other color. A game consists of four rounds.

Team competition: A team

continued on page 66



Zach Wooley of Lakeshore, AL lines up his shot with the help of his assistive device and the encouragement of his coach, Treva.

continued from page 65

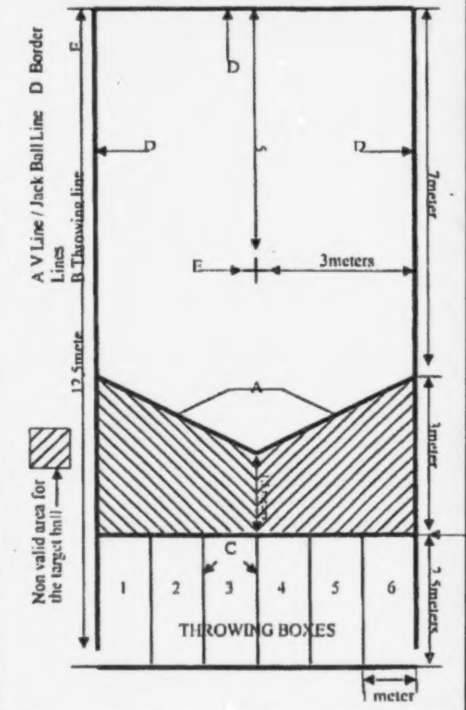
consists of three players. In team play, each of the three players throws two balls. Play continues just as in individual competition with the members of the team determining which player is to throw next. Team games consist of six rounds.

NDSA PROUDLY SPONSORS BOCCIA ATHLETES REGIONALLY, NATIONALLY AND INTERNATIONALLY.

Pairs competition: A pair consists of two players, each player throwing three balls. A pairs game consists of four rounds.

Players are required to stay within their playing box during play. The game not only involves use of arm muscles, grasp, release and aim, but requires the competitors to develop a strategy to prevent their opponents from scoring. In addition to the competitors themselves, therapists and teachers also love the game as a way to supplement school based programs. This game is played at a recreational level around the world. Additionally, there are regional, national and international competitions for boccia.

BOCCIA COURT LAYOUT



MIDWEST MOBILITY & DESIGN INC.
ACCESSIBLE TRANSPORTATION

DROP FLOOR MINIVANS
SPORT PICKUPS
4" x 6" DROP FLOORS
RAISED ROOFS & DOORWAYS

- Rental Vans
- In Stock Units
- New & Used
- Ship Anywhere
- Financing
- Trade-ins

WWW.MIDWESTMOBILITY.COM

1-800-809-3738
NATIONWIDE

1-847-923-9892
CHICAGOLAND AREA

Since 1972
An All-Star Distributor of Braun Mobility Products

★★★★★
5 Star Dealership

Circle #55 or visit www.eparent.com/adinfo

SUREHANDS®

Anchors in different locations when needed.

Gary L., *accountant*, Warwick, NY - Becker's MD

At last, a Lift & Care℠ system as versatile as a pair of hands...and portable, too.

It's a motorized transfer device,
a positioning tool *for posture seating*,
a bathing support,
a hygiene helper *for toileting or diapering*,
a floor space-saver,
a standing support *for some*,
a dressing assistant,
and a back-saver *for carers*.

SUREHANDS LIFT & CARE SYSTEMS
Portable and permanent solutions for homes and workplaces.
1-800-724-5305
e-mail: info@surehands.com • website: www.surehands.com

Circle #66 or visit www.eparent.com/adinfo

For athletes who are not able to grasp and release the ball due to weakness, lack of available movement or poor hand control, assistive devices may be used. Generally, a competitor will begin with something quite basic like a five foot piece of four inch PVC pipe cut in half to make a half-circle trough. The competitor directs an assistant, who sits with his back to the court, how to aim the chute. The directions may be verbal, through eye gaze, hand movements or utterances. Once the chute is aimed to the competitor's satisfaction, the ball is placed in the chute where the competitor can release it. Release may be with the hand, chin, headstick or handstick. The competitor must be in control of the ball at the time of release. The chute can be angled to aim the ball and can be raised or lowered to control the speed of the ball when it is released, determining the distance it will travel. As competitors gain skills, more specific assistive devices are usually made to allow them better control. Each competitor can determine the design of her device as long as it meets rule requirements and the competitor is able to control the release of the ball.

NDSA proudly sponsors boccia athletes regionally, nationally and internationally. Most recently, a team traveled to Portugal in June to compete in the World Championships. These athletes love to discuss boccia and would be happy to share their experiences with you or your child. The NDSA or one of the athletes can be contacted via e-mail (boccia@ev1.net) or by mailing questions to NDSA at the address below. Additional information on boccia, boccia rules, beginning assistive device ideas and pictures of some of the athletes in action are available from NDSA. EP

Debbie Akins has been NDSA's Boccia Sports Manager for the past 10 years. She has been coaching boccia since 1983 at a local, national, and international level. By profession, Debbie is an Occupational Therapist practicing in Ft. Worth Independent School District.

FOR MORE INFORMATION CONTACT:

The National Disability
Sports Alliance
25 West Independence Way
Kingston, RI 02881•(401) 792-7130
E-mail: boccia@ndsaonline.org
Web site: http://www.ndsaonline.org

R.E.A.L. Design Introduces VIVO™
The New Multi -Therapy Pony

Children will love VIVO, the playful, spirited little pony with the head that bounces when moved and a colorful beaded tail. Parents and therapists will appreciate the valuable skills children gain by playing on VIVO because it functions as a balance rocker or gait trainer by simply interchanging the legs which snap on and off easily. As a rocking horse, VIVO promotes balance reaction skills and upper body postural development. As a gait trainer, it provides incentive for a child to learn ambulation skills. The soft upholstered seat back, with molded laterals, is height adjustable to position children comfortably and securely for rocking or learning to walk. Accessories are available for adapting VIVO to a child's positioning needs.

R.E.A.L. DESIGN 1.800.696.7041 Fax: 1.315.429.3071
www.realdesigninc.com

Circle #78 or visit www.eparent.com/adinfo

Way to Go: Positive Reinforcement Programs For Your Child with Attention Deficit/Hyperactivity Disorder (ADD/ADHD)

by Jeanne A. Marron, PhD

There are many undesirable behaviors that you may want to decrease in your child. However, it is often better to try to find a way to increase a desirable behavior that may be an alternative to the undesirable behavior. For example, you may want to decrease the time that your child takes in resisting sitting down and doing homework. Another way to look at this is to increase the desirable behavior of sticking to a schedule and therefore sitting down to do the homework in a specified amount of time.

REINFORCEMENT

Reinforcement is something that is designed to increase behavior. There are two types of reinforcement: Positive and Negative. Positive reinforcement increases behavior when you add or give something following the behavior. Negative reinforcement increases behavior when you take something away following the behavior.

DEFINING BEHAVIOR: WHAT IS THE TARGET

The first step in setting up a positive reinforcement system involves defining the targeted behaviors.

GUIDELINES FOR DEFINING TARGET BEHAVIORS

I. Whenever possible, try to define the behavior in positive terms. (see chart below)

II. Narrow your range of focus

Be selective in identifying your target behaviors. Trying to change too many behaviors at one time is likely to fail. When selecting target behavior(s) think of the importance in terms of the following factors:

- Functional level - Where is the child in terms of behavior? What is the child able to do? If your goal is to be able to enjoy going out to a restaurant but one of your child's behaviors is the inability to stay seated at a table for more than five minutes, then changing the behavior must begin at that level
- Importance of that functional level - Prioritize according to your values. Does the behavior interfere with goals set for the child? You have decided that you want your child to have more academic success therefore it is impor-

DEFINING DESIRABLE BEHAVIORS

Here are some examples of to re-defining the undesirable behaviors in terms of desirable behavior:

UNDESIRABLE BEHAVIOR:	RE-DEFINITION:
Nail biting	Lets nails grow; Keeps fingers out of mouth
Fidgets	Stays still in chair for 10 minutes
Talks on and on	Keeps focused on one topic long enough to express a thought or need
Disorganized	Remembers to bring homework home

Ask the Doctor addresses issues of concern to our readers. Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products. Send questions to: Ask the Doctor, Exceptional Parent, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com.

DEFINING BEHAVIORS IN SPECIFIC TERMS

Breaking down behaviors into their component parts and re-defining them in positive terms is often helpful.

Behavior	Sub-behaviors (broken down into specific behaviors)	Re-definition (the desirable behavior)
Always on the go	a) Fidgets b) Gets out of chair five times in 10 minutes	Stay still in chair for 10 minutes

tant to get the child to focus.
Therefore, sitting quietly in class

- Quality of life - Whose quality of life are you trying to improve? Will changing this behavior alter life positively? If your child wants to participate in team sports but their behavior is affecting involvement with others, changing the behavior is important for the child's success. If you see academic success as an important goal, but your child would rather spend time involved in sports, your goal will be harder to accomplish because there will be a conflict.
- Practical issues - Factors such as time and ability to monitor behavior should be taken into consideration when targeting a behavior to change. For example, if the behavior you choose to improve or change occurs mostly in school, you will not be able to monitor it directly.
- Detail - Be very specific when defining the behavior. This may involve breaking larger behaviors into smaller parts and working on them one at a time.

III. The target behavior has to be measurable

The behavior has to be something you can truly assess in terms of change. This may involve the number of times something occurs or the amount of time something lasts or the frequency of it.

- Measuring Behavior - In order to see changes in behavior(s) you need to have a clear sense of the baseline, or what is "normal" for your child. How often does the behavior occur now? How often would you like it to occur?

SELECTING REINFORCEMENTS

In selecting reinforcements, use what already motivates your child. This does not have to be a material thing, but can be time on a preferred activity. Be aware that what motivates children one day may not motivate them the next.

You may want to have a variety of reinforcement available. For example, selecting from a bowl of activities, or a point system that earns different prizes. When possible, have your child play a role in selecting the reinforcements.

SELECTING REINFORCEMENTS

Think about your child's likes and dislikes and use what already motivates your child. Make a list of five things your child likes and a list of five activities he or she enjoys. A reinforcement does not have to be a "prize." It could be time playing a game with you, time on the computer, a trip to the library, etc. Remember that what motivates a child one day may not do the trick next week. You may want to put together a "treasure box" for variety, or provide other methods of choice. Be practical - reinforcements are meant to motivate and do not have to be expensive or elaborate.

DESIGNING A REINFORCEMENT PROGRAM FOR VARIOUS AGE LEVEL CHILDREN

Different age levels require different systems. Younger children work best with systems that furnish a very short delay between the behavior and the reinforcement. As a child ages, the reinforcement system can become more complex, with longer delays between behavior and reinforcement.

Try to get your child to make a "contract" to try the system. The greater the child's involvement in setting up the system and affirming efforts to comply, the more likely it will be for the system to succeed.

For all ages, pair the reinforcement with positive verbal feedback. This is the route to internalization. You want your child to take pride in his or her accomplishments. It is this internal sense pride that will carry the behavior forward in the future.

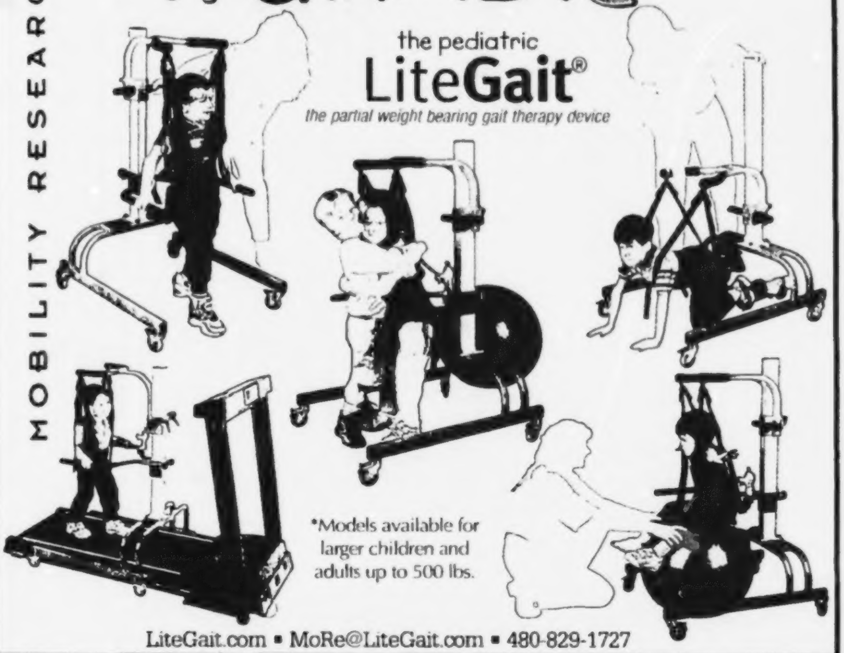
REVIEWING AND FINE-TUNING YOUR REINFORCEMENT PROGRAM

Be patient and give your system a fair trial. Identify a "review day" to assess your system. If it is not working, do some trouble shooting. What factors are interfering? Were you being realistic in the target number of behaviors needed to earn the reinforcement?

If it is working, continue the system for another period of time and if needed, alter the system. Wait to gain suc-

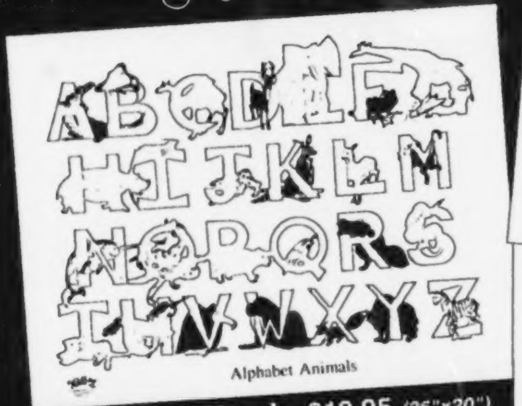
continued on page 70

Up & Walking...and so much more
with WalkAble™
MOBILITY RESEARCH
the pediatric
LiteGait®
the partial weight bearing gait therapy device



*Models available for larger children and adults up to 500 lbs.
LiteGait.com ▪ MoRe@LiteGait.com ▪ 480-829-1727
800-332-WALK WalkAble.com
Circle #56 or visit www.eparent.com/adinfo

Learning by Association! The Art of the Alphabet!



Alphabet Animals

The Bears

The Bunnies

Alphabet Animals $19.95 (26"x20")
Laminate Any Poster + $3.95 ea.
100% SATISFACTION GUARANTEED!
Bears or Bunnies $9.95 ea. (22"x18")
Kid's #1®
Help your child know the alphabet before kindergarten!
Learning by Association
Copyright 2002 • All Rights Reserved Kid's # 1, Inc. Minneapolis, Minnesota
Receive FREE Bears or Bunnies poster with purchase of each Alphabet poster!
When purchasing any two or more posters, receive $1.00 DISCOUNT each poster!
Order 24 hours a day/7 days a week
1-888-844-5200 or www.kids-1.com
VISA • MASTERCARD • AMEX • DISCOVER
Add $7.95 s&h • Minnesota residents add sales tax
INQUIRE FOR VOLUME DISCOUNTS OR WHOLESALE SC AGN005
Circle #47 or visit www.eparent.com/adinfo

continued from page 69

cess in one behavior before targeting another.

THE ABCS OF BEHAVIOR: BECOMING AN OBSERVER OF YOUR CHILD'S BEHAVIOR

ANTECEDENTS: What led up to the behavior? What was the situation or context in which the behavior occurred?

BEHAVIOR: What is the behavior? Specify exactly what behavior occurred.

CONSEQUENCES: What happened in response to the behavior? What was the response of you or others to the behavior?

Positive reinforcement systems target behavior through positive consequences aimed at increasing the desirable behavior. Remember to examine the the antecedents of a behavior as sometimes the context needs to be altered for the behavior to change.

MAKING IT WORK

These are just some basic tools for structuring a reinforcement program. You and your child may be able to find new tools to help you accomplish your goals together. Be sure to approach the positive reinforcement program with a positive attitude and make it a fun and successful experience for your child. EP

This article is based on Dr. Marron's presentation at the Northern New Jersey Maternal/Child Health Consortium conference "ADHD: Maximizing Potential," Woodcliff Lake, NJ, May 17, 2002.

Jeanne A. Marron, PhD, is a clinical psychologist and has been an instructor, clinician and researcher for more than 18 years. She is also the clinical supervisor for the Asperger's yndrome Program.

Charles C Thomas
PUBLISHER • LTD.

2600 South First Street
Springfield, IL 62704

Forthcoming releases from Charles C Thomas, Publisher!

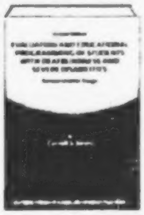
PSYCHOLOGICAL AND EDUCATIONAL TEST SCORES
What Are They?
Published 2002, 196 pages
Marty Sapp
hard ISBN 0-398-07258-2
paper ISBN 0-398-07259-0

PEDIATRIC MUSIC THERAPY
To be published 2002, 344 pages
Wanda B. Lathom-Radocy
hard ISBN 0-398-07301-5
paper ISBN 0-398-07302-3

ENDING DISCRIMINATION IN SPECIAL EDUCATION
(2nd Ed.)
To be published 2002, 150 pages
Herbert Grossman
paper, ISBN 0-398-07304-X

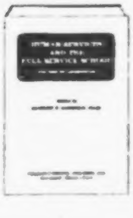
DEVELOPING AND IMPLEMENTING IDEA-IEPs
An Individualized Education Program (IEP) Handbook for Meeting Individuals with Disabilities Education Act (IDEA) Requirements
Published 2001, 274 pages
Edward Burns
$59.95, hard ISBN 0-398-07122-5
$40.95, paper ISBN 0-398-07123-3 (displayed)

EVALUATION AND EDUCATIONAL PROGRAMMING OF STUDENTS WITH DEAFBLINDNESS AND SEVERE DISABILITIES
Sensorimotor Stage (2nd Ed.)
Published 2001, 294 pages
Carroll J. Jones
$45.95 paper ISBN 0-398-07216-7 (displayed)



AUTISM AND POST-TRAUMATIC STRESS DISORDER
Ending Autistic Fixation
Published 2000, 136 pages
Kenneth Lenchitz
$36.95, cloth ISBN 0-398-07096-2
$19.95, paper (displayed) 0-398-07097-0

HUMAN SERVICES AND THE FULL SERVICE SCHOOL
The Need for Collaboration
Published 2000, 128 pages
Robert F. Kronick
$18.95, paper ISBN 0-398-07063-6



HOME IS WHERE THE ART IS
An Art Therapy Approach to Family Therapy
Published 2001, 224 pages
Doris Banowsky Arrington
$61.95, hard ISBN 0-398-07160-8
$42.95, paper ISBN 0-398-07161-6

EDUCATIONAL INTERVENTIONS AND SERVICES FOR CHILDREN WITH EXCEPTIONALITIES
Strategies and Perspectives (2nd Ed.)
Published 2001, 304 pages
George R. Taylor
$66.95, cloth ISBN 0-398-07112-8
$44.95, paper ISBN 0-398-07113-6 (displayed)

RESEARCH IN SPECIAL EDUCATION
Designs, Methods, and Applications
Published 2001, 268 pages
Phillip D. Rumrill, Jr., & Bryan G. Cook
$56.95, cloth ISBN 0-398-07172-1
$38.95, paper ISBN 0-398-07173-X (displayed)

Programmed Therapy FOR STUTTERING in Children and Adults (2nd Ed.)
Published 2000, 360 pages
Bruce P. Ryan
$79.95, hard ISBN 0-398-07106-3
$54.95, paper ISBN 0-398-07107-1

Contact us to order books or a free catalog with over 811 titles

Call 1-800-258-8980 or 1-217-789-8980 or Fax 1-217-789-9130
Complete catalog available at www.ccthomas.com • books@ccthomas.com

Books sent on approval • Shipping charges: $6.95 U.S. / Outside U.S., actual shipping fees will be charged
Prices subject to change without notice

Circle #25 or visit www.eparent.com/adinfo

The Double Whammy:

Tourette Syndrome and Associated Disorders as They Impact Families

by Jan Blacher, PhD

You've probably seen the motor or vocal tics in characters on the TV shows Ally McBeal or The Practice. You may have seen them displayed by children or adults at the local mall, or at school or even on a college campus.

If you're a die-hard baseball fan, it is likely you know about professional baseball player Jim Eisenreich (EP's Role Model Feb. 1997):

"His troubles began when he was eight. Jim was a good ball player. But sometimes, while he was playing, his body would start twitching. His neck jerked and his arms thrashed wildly. His eyes, nose, and mouth twisted into the funniest faces."—(from The MacMillan Baseball Stories, "All Eyes on Eisenreich" Egan, Friedmann, & Levine, 1992, p. 97)

I am calling your attention to a disorder known as Tourette syndrome (TS) or, Tourette's disorder. The disorder is characterized by vocal and motor tics. Although the tics associated with TS can sometimes be frequent and severe, more often they are not. TS typically occurs in children who are of normal intellectual functioning, and who are aware of their often bizarre behaviors.

What is Tourette Syndrome (TS)?

Complete descriptions of TS are provided on the Tourette syndrome Association Web site (see pg 77) and in the American Psychiatric Association's most recent Diagnostic and Statistical Manual of Mental Disorders (known as the DSM-IV). The APA defines a tic as "a sudden, rapid, recurrent, nonrhythmic, stereotyped motor movement or vocalization." The main criterion for diagnosing TS is the occurrence of multiple motor tics and one or more vocal tics that occur throughout a period of more than one year. By definition, though, TS must have its onset by age 18. Finally, tics associated with TS cannot be due to the effects of a medication (e.g., psychostimulants like methylphenidate) or some other general medical condition (e.g., post-viral encephalitis).

Many individuals associate TS with the random uttering of obscenities; indeed, this has received the most focus in the media and, unfortunately, in the general vernacular. Ironically, this symptom of TS, known as "coprolalia," occurs in less than 10 percent of people with TS, and is not even a criterion for the diagnosis of the disorder. Slightly less alarming than coprolalia are various other vocal tics (e.g., growls, grunts, coughs, sniffs). Most common are simple motor tics, such as eye blinking. Complex tics include touching, twirling when walking and deep knee bends. Tics always vary over time in their number, frequency, anatomical location, complexity and severity.

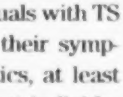
The process of distinguishing TS from other disorders, or differential diagnosis, can be complicated because of the many disorders that are similar in appearance and type. In fact, the diagnosis of an individual can change over time, from a transient tic disorder, or chronic motor or vocal tic disorder, to TS. However, according to Eric Saslow, a neurologist at UCLA, the management of these related disorders would be similar. Although tics are considered involuntary, many individuals with TS have some control over their symptoms and can suppress tics, at least for a time; eventually, most individuals with TS do have to release their symptoms. Dr. Saslow notes that this situation, unfortunately, leads some people to believe that tics are actually "voluntary" and could be controlled, if only an effort were made.

How many people have TS?

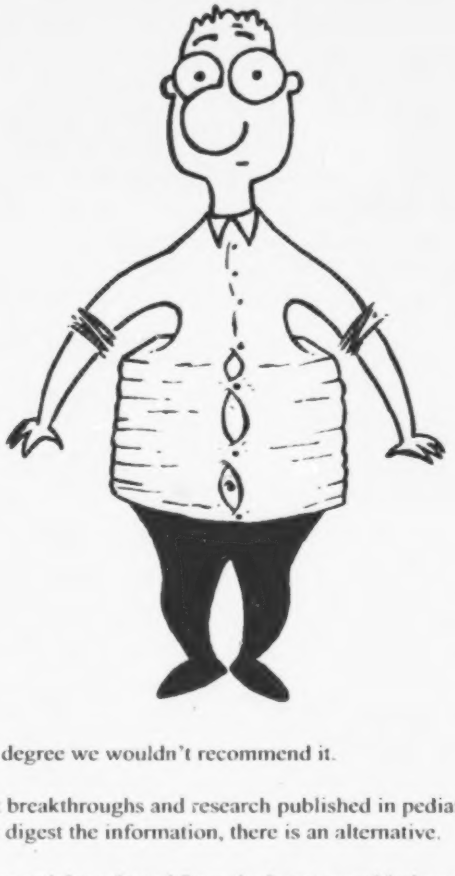
According to the DSM-IV, TS affects all racial and ethnic groups. It has been reported in children as young as 2 years of age, though the onset of tics is most often reported around age 6 or 7. While TS appears in adults at the rate of about one or two per 10,000, children are affected at the rate

continued on page 74

Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, where she has been a researcher for 20 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of mental retardation, dual diagnosis and the transition to adulthood. Dr. Blacher has developed **Research Reflections** as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to **Research Reflections** and any suggestions you might have. Send e-mail to: jan.blacher@ucr.edu.



As our volunteer clearly demonstrates, 21* pediatric medical journals can be quite difficult to digest.



In fact, unless you have a medical degree we wouldn't recommend it.

If you have an interest in the latest breakthroughs and research published in pediatric journals, but don't have the medical training required to easily digest the information, there is an alternative.

ChildHealthMonitor.org publishes articles adapted from the latest monthly issue of each of the world's leading pediatric publications*. The information is the same. The difference is that much of the medical jargon is replaced with everyday language. It's also online which means that anyone with an Internet connection can now have instant access to reliable, useful information on the latest advances in treatment, prevention, and caring for kids.

Simply, visit **www.childhealthmonitor.org** and you too can have unlimited access to hundreds of simply written articles on up-to-the-minute pediatric discoveries.

We think you'll find this option much more palatable. (Our volunteer did.)

* Acta Paediatrica, Archives of Disease in Childhood, Archives of Pediatrics and Adolescent Medicine, Brain and Development, British Medical Journal, Child: Health, Care and Development, Developmental Medicine and Child Neurology, European Journal of Pediatrics, Journal of Adolescent Health, Journal of Child Psychology and Psychiatry, Journal of Paediatrics and Child Health, Journal of Pediatric Psychology, Journal of Pediatric Surgery, Journal of Pediatrics, Journal of the American Academy of Child and Adolescent Psychiatry, Journal of the American Medical Association, The Lancet, New England Journal of Medicine, Pediatric Infectious Diseases Journal, Pediatrics, and Research in Developmental Disabilities

CHM

ChildHealthMonitor.org

research reflections

continued from page 72

of 5 to 30 per 10,000. The National Institutes of Health estimate that 100,000 Americans have full blown TS; this could be even higher if individuals with chronic tics or transient childhood tic disorder are also included.

Some claim that TS seems to be more common among school children today, and shares dramatically increasing rates associated with autism and attention deficit hyperactivity disorder (ADHD). Indeed, in a study published in 2001 in the journal *Neurology*, by Roger Kurlan and colleagues, the rate of TS among school children in the general population is cited as 50 to 75 times higher than has been traditionally thought. The investigators examined 1,596 school children and found that about 27 percent of those in special education had some kind of tic disorder, with seven meeting diagnostic criteria for TS. Twenty percent of regular students demonstrated tics, with almost 4 percent meeting diagnostic criteria for TS.

Double Whammy: What other disorders are associated with TS?

As if Tourette syndrome weren't challenge enough, these children often must struggle with adverse social reactions, learning difficulties, and even additional psychiatric disorders. Research suggests that the social and emotional difficulties that often go along with TS are more problematic for daily adaptation than the motor and vocal tics. Diane Shader Smith, a mother of a child with TS, realistically portrays what life is like for a ninth grade boy with Tourette syndrome in her novel, *A Test of Will:*

"English was easily his worst subject, largely because Will found it almost impossible to read a chapter from his lit book. Will blamed his reading difficulties on his Tourette Syndrome, a neurological disorder he'd been diagnosed with in third grade that was characterized by motor and vocal tics. It was a strange disorder, Will often thought, because it caused all kinds of other problems that had nothing to do with tics."—(Smith, 2002, p.3)

Two disorders often associated with TS are attention deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder. In one study, conducted in Sweden, Bjorn Kadesjo and Christopher Gillberg documented the types and numbers of disorders that

Never in my Wildest dreams...

"WHEN I FIRST CAME TO CROTCHED MOUNTAIN OVER 10 YEARS AGO, activities that were second nature prior to the automobile accident were challenging tasks. Today I am a college graduate and also have my drivers license.

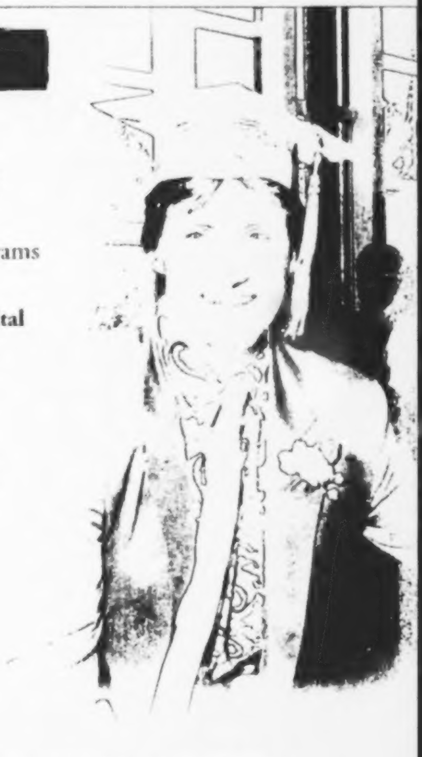
Never in my wildest dreams would I have been able to do half of what I've achieved without the encouragement and help that I received at Crotched Mountain! I want to thank everyone at Crotched Mountain for helping me get my life back!"

—Brent Reagan '93
Crotched Mountain School

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953



For more information, call 800-966-2672
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@cmf.org

CROTCHED MOUNTAIN OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #30 or visit www.eparent.com/adinfo

co-existed in children with TS. They screened a clinic sample of 58 children already registered as having TS at a county-wide tic disorder clinic. Two-thirds of the clinic sample met criteria for ADHD. Two-thirds also scored above a cut-off on a screening instrument for Asperger's disorder or high functioning autism. The authors suggest the intriguing possibility that TS may also be under-diagnosed in those with pervasive developmental disorders (such as high functioning autism) because tics may be misdiagnosed as repetitive, stereotyped behaviors associated with autism.

Researchers refer to the appearance of multiple disorders as comorbidity. From the perspective of their impact, on both the child and his or her family, having TS plus another significant disorder constitutes a "double whammy."

How does TS impact families?

Researchers have studied the impact of TS, and they have done so in a variety of ways. School functioning of children with TS is clearly affected. In several studies, teachers have reported that children with TS are less popular and more withdrawn than control children (i.e., those with no known disorder). Other researchers have compared the impact of TS without any comorbid disorders to the impact of TS plus some other disorder.

One disorder in particular that has a negative impact on the child's functioning at school and on family functioning at home is ADHD. Children with ADHD are characterized as having difficulties with self-regulation, including inattention, hyperactivity and impulsivity. Children with ADHD without TS, often have social and peer difficulties, higher rates of conduct problems and aggression in school, and generally poor adaptive behavior skills. Not surprisingly, then, the combination of ADHD and TS results in greatly heightened family stress.

Alice Carter and her colleagues at Yale University studied how TS affected family functioning. Their findings, published in the *Journal of Child Psychology and Psychiatry* in 2000, were enlightening. They compared three groups of children: No TS, TS alone, and TS with comorbid ADHD. The children with TS, even without comorbid ADHD, had more school and attentional problems than the control (no TS) children. This makes sense, of

continued on page 76

VÖLKER
Better Beds
The healthcare bed in disguise.
That's the beauty of the Völker Style...
1
2
3
4
5
6
7
8
1. Electric operation via a hand control or nurse console (optional). **2.** Absolutely secure braking. **3.** Electric push button casters. **4.** Stable height adjustment 15 1/2–31 1/2" (13 3/4–27 1/2" optional). **5.** Trendelenberg/reverse Trendelenberg (optional). **6.** Easy to move on disappearing casters. **7.** Tilt-in-space positioning that allows for sitting (cardiac) or reclining chair. **8.** Disappearing full lenght side rails.

For more information call 1-800-321-4240

Hertz Supply Co., Inc. · 4670 Schantz Rd., Suite A · Allentown, PA 18104 · www.hertzsupply.com

Hertz SUPPLY

Circle #41 or visit www.eparent.com/adinfo

339

continued from page 75

course, because children with TS have motor inhibition difficulties and are often distracted while trying to suppress their tics in school settings.

Carter's group further found that parent-rated child attentional problems and the range of maladaptive behaviors were highest in the TS + ADHD children, followed by TS alone, and then control children. We might, then, infer a continuum of impact on families, a finding corroborated by other studies examining negative family impact in the presence of TS and co-existing disorders. In turn, as Carter had hypothesized, lower family functioning was associated with poorer social emotional adjustment in TS children, and more so when the child had comorbid ADHD.

Is the "Double Whammy" unique to TS?

Unfortunately, the answer is "NO." Children with an intellectual disability are at an especially high risk for behavior problems and a diagnosed mental disorder. In children with a primary diagnosis of mental retardation, this type of "double whammy" is called dual diagnosis. Most of the work on dual diagnosis has pertained to older children or adolescents, with reported prevalence rates of a psychiatric diagnosis (e.g., ADHD, OCD as noted above) three to four times those found in the typical population. Recent studies are beginning to find heightened rates in young children as well.

In our own work, conducted with Bruce L. Baker at UCLA and Keith Crnic and Craig Edelbrock at Penn State University, the emergence of the "double whammy" in children as young as 36 months of age was found. Children with developmental delays were three times as likely as their non-delayed peers to score in the clinical range on the Child Behavior Checklist, a commonly used instrument for assessing behavior problems. These behavior problems, scored by mothers and fathers, were stable over the year from 36 to 48 months.

Parenting stress was higher in the families of children with developmental delay, similar to findings from families of children with TS and from studies of families coping with many other disabilities. A lingering question has been whether heightened family stress represents a chronic reaction to intellectual disability per se or a reaction to

Training

A Special 20:4:80 Weekend Workshop in San Antonio
with Karen E. Pape, MD
Saturday - Sunday, July 27-28, 2002

Approach

There *is* a way to turn technology into kids' stuff. Join us and see what the TASC Approach is all about. TASC Life Span Systems explain when to consider TES, NMES and FES to achieve optimal results...The outcomes of Botulinum Injections, Baclofen Pumps, Rhizotomy and Multilevel Surgeries may change with a focused training program.

Systems

This program is designed to teach "Coaching 101" for families of children with neurologic disabilities. Life expectancy for children with cerebral palsy and spina bifida now approaches normal and "normal" is 80-90 years. 20:4:80 means twenty years of preparation for eighty years of life. Families need to become experts in their child's condition. Insurance companies may not pay for a lifetime of therapy. All children need help preparing for a lifetime of self-care.

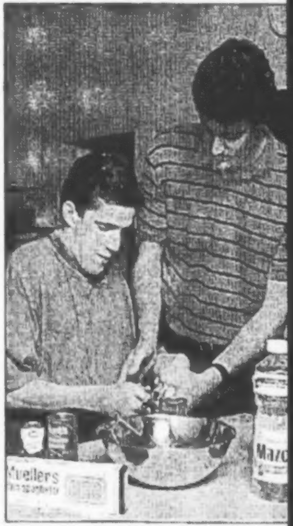
Coaching

Course fee $250. Discounts available. Book early ... space is limited. To register, call 1-800-351-0016 (toll free) or visit www.tascnetwork.net.

COPYRIGHT 2002 TASCNETWORK

Circle #23 or visit www.eparent.com/adinfo

LIVING & LEARNING



STUDENTS AT THE EVERGREEN CENTER learn to live in the community and reach their full potential. Our Basic Skills and Behavior Development Centers, community residence programs and supportive staff combine to create a caring environment allowing students to achieve a greater degree of personal independence.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631

Serving students with developmental, medical and behavioral needs since 1981.

Circle #34 or visit www.eparent.com/adinfo

340

the often-associated behavioral challenges that these children present. In our analyses, child behavior problems were a much stronger predictor of parents' stress than the presence of or degree of cognitive delay. Furthermore, we found that over time, an interactional process was occurring, similar to Alice Carter's findings with TS families: High levels of parenting stress contributed to a worsening in child behavior problems over time, and high incidences of child behavior problems contributed to a worsening in parenting stress.

What are the implications of recent research for families?

The finding that parenting stress is related much more to child behavior problems than to the core symptoms of disorders like Tourette syndrome should be good news to service providers for several reasons. First, there is considerable evidence that behavior problems can be reduced successfully through psychological and pharmacological interventions. Second, knowing that there are greater social and emotional risks to families associated with TS, professionals can be on the lookout for evidence of family stress, and they can monitor such stress to be sure that families are coping adequately. They may also want to suggest family counseling or support services. Third, social skills training for children and adolescents with TS can help to improve peer relations and friendships. Finally, and more broadly, school-based interventions could help to reduce the stigma associated with tics.

A list of resources mentioned in this column may be obtained by e-mailing requests to: epedit@aol.com.

For more information on Tourette syndrome, see the following Web sites:

Jim Eisenreich Foundation for Children with Tourette Syndrome:
http://www.tourettes.org

Tourette Syndrome Association
http://www.tsa-usa.org

In closing...

More good news is that Jim Eisenreich finally found a doctor who diagnosed his tics and twitches as Tourette syndrome, and he received medication that all but eliminated them. In 1989 he was voted the Kansas City Royals' most valuable player.

The boy, Will, in the novel excerpted here, achieved academic and social success, and even captured the attention and affection of the girl of his dreams! EP

THE MELMARK SCHOOL
2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Our approved private day and boarding school serves
children ages 5-21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Acquired Brain Injuries
- Cerebral Palsy
- Mental Retardation
- Neurological Disorders

Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

We Offer Your Child:

- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK Ext. 636 or email admissions@melmark.org

Circle #53 or visit www.eparent.com/adinfo

PART XIII

Sports Injury Prevention and Trauma

by Manfred Friedman, DDS

Traumatic injuries to the teeth are among the most common and disturbing injuries to occur in children and adults with developmental disabilities. Although a significant number of injuries in both children and adults with developmental disabilities result from ambulatory and seizure disorders, these injuries can take place during some forms of sporting activity. It is important to understand that not all injuries will occur in formal sports. Children will often injure themselves during a friendly hockey game on a local street or while shooting hoops. Injuries can range from a small crack in the tooth enamel to complete avulsion (pulling out) of the tooth from the mouth. This article will deal with prevention of injuries during sporting activities, first-aid treatment that can be administered to the person before visiting a dentist and some of the recent techniques used to restore broken teeth.

Prevention of injuries to the teeth

Injuries to the teeth will happen most often when children are playing in either an organized sporting activity or during casual play with their friends. During casual play it is very difficult to prevent injuries as contact generally occurs randomly. Usually the child will fall and hit his/her face, lacerating tissues and often damaging a tooth or teeth. You can only advise your child to be careful when playing; should an injury occur, seek treatment immediately, especially if a tooth has been knocked out of the mouth. Children with very protruding teeth, such as those often seen in individuals with Cerebral palsy, are more prone to injuring their teeth after experiencing a blow to the face and teeth. When possible, the child should have orthodontic treatment to straighten and align the teeth. If the child or adult has an ambulatory or seizure disorder and is prone to falling, the use of a face protector should be considered. Fortunately, the majority of these disorders are controlled with medications, reducing the incidence of injury to the face and teeth.

Organized sporting activities

Any child or adult who is engaged in organized sporting activities which may result in contact with another athlete during the activity should wear a mouth guard to prevent injuries to the teeth and supporting soft tissues.

Mouth guards

Mouth guards are thin, flexible u-shaped pieces of plastic that are worn over the upper teeth when playing any contact activity, such as floor hockey, basketball, soccer, rugby, football, karate, tai-kwando, judo and boxing. Research has shown that these mouth guards act as shock absorbers when the person suffers a blow to the jaws. The primary function is to prevent injury to the teeth, temporomandibular joints and soft tissues; even more important, it has been demonstrated that concussion injuries to the brain can be prevented by wearing a mouth guard. All parents should insist that any child who is involved in a contact sport be fitted with a mouth guard.

Mouth guards can be either custom-fitted by your dentist or purchased off the shelf at the local sports or drug store. To have a custom guard made, the child visits the dentist, who will take a mold of the upper jaw. This mold is sent to a dental laboratory where the mouth guard is vacuum-formed to the mold. The completed mouth guard is then placed over the teeth and because it fits very well, is very comfortable. High-quality off-the-shelf mouth guards that also function very well—the "boil and bite" variety—are available. The mouth guard is placed in boiling water to soften the plastic, then placed over the teeth of the person, who is instructed to bite down gently and suck in on the mouth guard. This adapts the guard to the teeth. The guard is then removed from the mouth and placed in cold water to set the plastic. While this type of mouth guard is not ideal, those of higher quality are acceptable alternatives to the custom-fabricated guard. The important thing is that the person must wear the mouth guard. Consult your dentist, who will advise you on the best type of mouth guard for your child. The dentist can custom design a guard depending on the type and nature of the sporting activity.

Treatment of injuries to the teeth

Any time a person has suffered an injury to the face and teeth, it is very important to determine if s/he has lost consciousness. If this is so, even if everything appears perfectly normal, take the person immediately to the local emergency room for examination. Remember that you might not see the injured person until some time after the accident. Once it has been determined that the person did not lose consciousness, any injury to the soft tissues of the face and teeth can be dealt with.

The Avulsed Tooth

The most severe injury to the teeth is the avulsion, occurring when the tooth has been knocked out of the mouth. If a primary (baby) tooth is accidentally avulsed, do not put it back in the mouth. The correct treatment is not to attempt to replant it, but to seek immediate dental attention and address the injury. If a permanenttooth is lost, time is of the essence in treating this type of injury. The longer the tooth is out of the

continued on page 80

Customized Smiles

Everyone is different. Different shapes. Different sizes. Different needs. That's why at Danmar we customize our products for each individual. Seating and positioning devices which fit to a T. Helmets custom-designed for pony tails or buzz cuts. Swim aides so secure you're a fish in the water. You have a special need. We have a special product, one custom made for your smile.

Website: www.danmarproducts.com
Phone: (800) 783-1998

DANMAR

Special Products for special needs since 1968.

Danmar Products, Inc., 221 Jackson Industrial Drive, Ann Arbor, MI 48103 USA

Circle #31 or visit www.eparent.com/adinfo

continued from page 79

tooth socket, the less chance it will have to be treated successfully. The best treatment is to replace the tooth in the socket immediately and visit the dentist for further treatment that might involve stabilization. If the tooth has fallen in dirt, it should be washed off—holding the tooth by the crown only—and then replaced in the socket. Again, go straight to the dentist. Do not be concerned if you put the tooth in the wrong way; the best place to store the tooth is in its own socket, root side first. If you are uncomfortable placing the tooth back in the socket, place it in a glass of ice cold milk. If the person is high functioning you can place the tooth under the tongue or in the cheek pouch; saliva is an excellent storage medium. You must instruct the injured person to be very careful not to swallow the tooth. Proceed to the dentist or emergency room, where the tooth will be placed in a special preserving solution until the person can be treated.

Do not wrap the tooth in a dry handkerchief or piece of plastic; it is very important that the tooth remain moist during its trip to the emergency room or dentist. If you are in a facility which has a special "tooth saver container" for avulsed teeth, place the tooth in the container and go to the dentist immediately. Time is critical. The biggest problem with a tooth that has been avulsed is that the tissues on the root surface become dehydrated, greatly reducing the chance of successfully replanting the tooth.

Repairing broken teeth

For teeth that have been chipped, try to locate the broken piece, place it in water and take it with you to the dentist. The piece can sometimes be bonded onto the tooth, restoring its aesthetic appearance. If you cannot find the piece, the dentist will be able to repair the tooth almost to its original color and shape using current bonding techniques. If the piece is lost and the person has a lip laceration, an x-ray may be necessary to ensure that the piece is not embedded in soft tissue.

Bonding

The dentist will clean the broken tooth surface very well with a mild acid, which prepares the tooth surface for bonding. The dentist will then

Anderson School

Building A Tradition of Service for Over 78 Years

Anderson School provides the highest quality programs possible for children (ages 5-21) and adults with autism and other developmental disabilities. Anderson School is an educational residential community committed to an ongoing and fully integrated support network for their families and guardians. As an organization, Anderson School constantly strives to provide an enriched and positive climate filled with educational, cultural and recreational activities designed to foster continuous growth, independence and social interaction.

Located near historic Hyde Park (approximately 95 miles from midtown Manhattan) on a scenic 100 acre wooded estate overlooking the Hudson River, Anderson School serves all of New York State and welcomes out of state applications.

Now Accepting Referrals

- Residential and day students welcome
- Students accepted throughout the year

Call Kate Haas, Director of Admissions (845) 889-4034 Ext. 534
4885 Route 9, Box 367, Staatsburg, New York 12580-0367
www.andersonschool.org E-mail: katehaas@andersonschool.org

Circle #18 or visit www.eparent.com/adinfo

apply a bonding agent to the tooth and cure it with a special curing light. Now the tooth can be built up with very life-like materials, duplicating the shape and color of the original tooth. In most cases it is almost impossible to distinguish between the natural tooth and bonded repair. The repairs can often be made without the use of a local anesthetic, as the tooth does not have to be drilled at all, and the procedure is almost painless. However, if the nerve (pulp) of the tooth is involved, the dentist may have to use local anesthetic before treatment. Today "nerve treatments" (root canals) can be completed very rapidly thanks to advanced technology and materials. In a young child who has damaged a tooth and exposed a nerve, the treatment will normally take one or two visits. Following the nerve treatment, the dentist will restore the tooth to its normal function and appearance.

Sometimes a tooth may darken or discolor following trauma. If the tooth is a primary (baby) one, treatment is determined by the age of the patient and the development of the dentition, as this tooth will eventually be replaced by its permanent successor. A permanent tooth can be bleached, or even veneered, using bonding to restore its original color. If the tooth is very dark a porcelain crown or cap may be needed.

Implants

Today a person who has avulsed a tooth which cannot be replanted, or sustained a severe injury rendering the tooth (or teeth) non-restorable, can have it replaced with an implant. An implant can be likened to an artificial root that is imbedded in the bone, then covered with a crown to replace the tooth that was lost. Unfortunately, this treatment is only suitable for persons 18 years of age and older, because the jawbones have to complete their growth before an implant can be placed successfully. This treatment is especially useful for someone who has lost a single front tooth, as this treatment avoids cutting the adjacent teeth down to place a bridge. Bridges are an alternative method of replacing lost teeth. The teeth on either side of the lost tooth are reshaped by the dentist so that crowns can be placed on the

Continued on page 86

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel.** Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you.** Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #36 or visit www.eparent.com/adinfo

Getting information from

EP advertisers is

MUCH **FASTER**

ONLINE!

It's as easy as a click
of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers

CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in EXCEPTIONAL PARENT.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.

Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
17	ABILITIES EXPO	19
21	ADAPTIVEMALL.COM	60
18	ANDERSON SCHOOL	80
77	ADVANCED RESPIRATORY	12
19	ANNANDALE VILLAGE	6
22	BODYPOINT DESIGNS, INC.	35
23	BUSTIN & COMPANY	76
24	CAMPHILL SPECIAL SCHOOL	37
25	CHARLES C THOMAS	71
26	CHILDRENS HYPERBARIC CNTR@MIRACLE MT	52
27	COLUMBIA MEDICAL	31
28	CONNETQUOT WEST	46
29	CONVAID	7
30	CROTCHED MOUNTAIN REHAB	74
	CYCLETOTE CORP	64
31	DANMAR PRODUCTS	79
32	EDEN FOODS, INC.	26
200	EP LIBRARY PAGES	92-93
42	EP NEWBORN SCREENING DVD	40-41
199	EP SUBSCRIPTION	17-18
33	EQUIPMENT SHOP	60
34	EVERGREEN CENTER	76
35	FREEDOM DESIGN	47
36	FREEDOM MOTORS USA	81
37	GLOBAL POWER SYSTEMS INC	63
38	H.D.I.S.	30
39	HARD MANUFACTURING	16
40	HAVERICH ORTHO-SPORT, INC.	63
20	HEARTSPRING	29
41	HERTZ SUPPLY CO., INC.	75
	HOUSE AD	82, 95
46	INNOVATIVE PRODUCTS	99
47	KIDS #1, INC.	70
79	LAW OFFICES OF MICHAEL WEISS	45
48	LAWYERS, INC.	39
49	LIBERTY MOTOR COMPANY INC	C2
50	LITIGATORS, INC.	53
51	MARTHA LLOYD COMMUNITY SERV.	46
52	MATHENY SCHOOL & HOSPITAL	51
53	MELMARK	77
54	MET METROPOLITAN LIFE INS.	C3
55	MIDWEST MOBILITY AND DESIGN	66
56	MOBILITY RESEARCH	70
57	NOVARTIS NUTRITION	9
58	OCEAN HYPERBARIC CENTER	61
59	PRECISION FOODS	49
60	RED BARN ENTERPRISES	51
78	REAL DESIGN	67
61	SIGMA TAU	1-2
62	SNUG SEAT INC	11
63	SOUTH FLORIDA CNTR FOR HOPE	45
64	SOUTHPAW ENTERPRISES, INC.	50
45	ST. LOUIS CHILDREN'S HOSPITAL CONFERENCE	85
65	STEWART HOME SCHOOL	59
66	SURE HANDS INTERNATIONAL	66
67	THE BABY JOGGER COMPANY	58
68	THE CENTER FOR DISCOVERY	25
69	THE JOHN MERCK FUND	86
70	VAIL PRODUCTS	C4
71	VERIZON	5
72	VIEWPOINT MOBILITY LLC	37
73	WENZELITE MEDICAL SUPPLY	59
74	WHEELCHAIR GETAWAYS	58
75	WOODBURY PRODUCTS	45
76	WORLD CONGRESS	54-57

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

EP

has the information an "Exceptional Parent" like you needs

EP

Exceptional Parent

Subscribe on our website: www.eparent.com

and save

$5.00

For telephone orders call:

877-372-7368

To start your subscription to EP today, fill out the card near the front of this magazine or log on to

www.eparent.com

EXCEPTIONAL PARENT Free product & service information order card* **JULY 200**

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ____________________

Address ____________________

City ____________ State ______ Zip ______

Phone ____________ Fax ____________

E-mail ____________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No

If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist ^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist

^{10}☐ Other (please indicate) ____________

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No

If Yes, are you a: ^{13}☐ Other (please indicate) ____________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No

If yes, please explain ____________

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	2
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	5
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	7
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	10
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	12
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	15
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	17
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	20

*CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: December 31, 2002

BJUL

EXCEPTIONAL PARENT Free product & service information order card* **JULY 200**

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ____________________

Address ____________________

City ____________ State ______ Zip ______

Phone ____________ Fax ____________

E-mail ____________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No

If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist ^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist

^{10}☐ Other (please indicate) ____________

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No

If Yes, are you a: ^{13}☐ Other (please indicate) ____________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No

If yes, please explain ____________

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	2
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	5
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	7
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	10
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	12
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	15
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	17
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	20

*CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: December 31, 2002

347

BJUL

To start your subscription to EP today, fill out the card near the front of this magazine or log on to www.eparent.com

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

NO POSTAGE NECESSARY IF MAILED IN THE UNITED STATES

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer life for themselves and for their children.

Exceptional Parent's MISSION IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

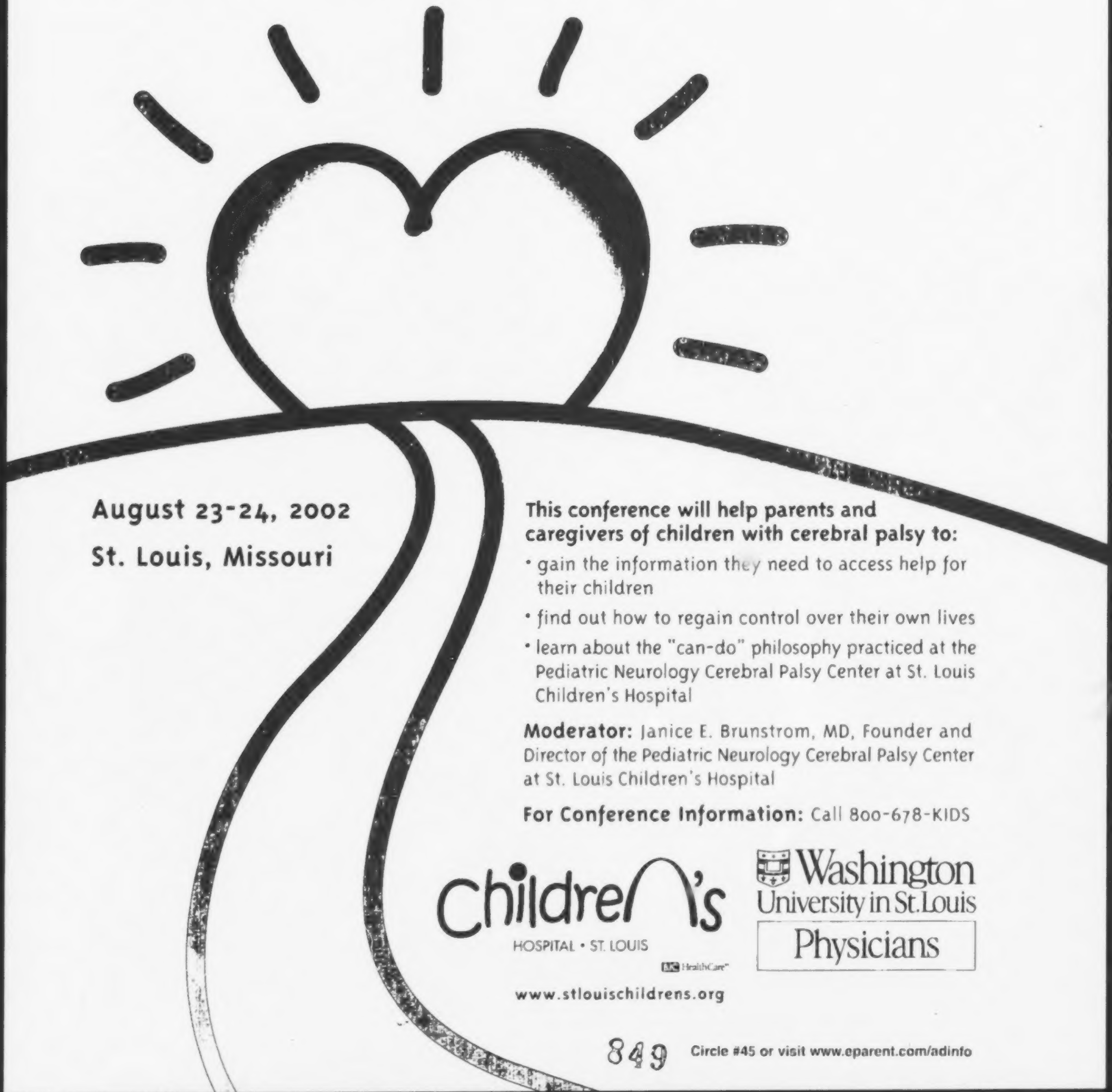
SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

Building The Road to Independence

A Conference for Families of Children with Cerebral Palsy



August 23-24, 2002

St. Louis, Missouri

This conference will help parents and caregivers of children with cerebral palsy to:

- gain the information they need to access help for their children
- find out how to regain control over their own lives
- learn about the "can-do" philosophy practiced at the Pediatric Neurology Cerebral Palsy Center at St. Louis Children's Hospital

Moderator: Janice E. Brunstrom, MD, Founder and Director of the Pediatric Neurology Cerebral Palsy Center at St. Louis Children's Hospital

For Conference Information: Call 800-678-KIDS

Children's
HOSPITAL • ST. LOUIS
BJC HealthCare™

Washington University in St. Louis
Physicians

www.stlouischildrens.org

Circle #45 or visit www.eparent.com/adinfo

continued from page 81

teeth. The two crowns are joined by a false tooth and the whole bridge is cemented onto the prepared teeth. This type of restoration is very good as long as the patient has very good oral hygiene. Other important considerations about implants are significant cost and the high level of patient cooperation required for the procedure.

The use of dentures to replace teeth in a person with developmental disabilities must be carefully evaluated, especially in those individuals with seizure disorders, as dentures can be displaced during a seizure episode. Your dentist will be able to evaluate the best replacement method for the individual.

If the tooth remains in the socket but has been knocked out of alignment, you can try to reposition it if the child or adult will allow you to do so. The best time is immediately after the accident, as the person will be a little shocked and will still allow you to touch the teeth. Again, visit your dentist as soon as possible. If your dentist is not available, take the person to the local emergency room. Unfortunately, emergency rooms are notorious for keeping patients waiting if an injury is not life-threatening, and sometimes this wait can compromise the success of treatment.

Remember, once the teeth have been repaired it is important to visit the dentist for regular follow-up visits to check that the teeth are functioning properly and healing well. It is not uncommon for the nerves—not only in the injured teeth but in the adjacent teeth—to deteriorate following trauma, so follow-up is very important. If the initial repair was made at an emergency facility or while away from the area, please be sure to tell your dentist that the person has had a traumatic injury to the teeth. The dentist will then take x-rays as necessary to monitor the traumatized teeth over time. **EP**

Manfred Friedman, DDS, is an Assistant Professor in the division of operative dentistry and endodontics at the School of Dentistry, University of Western Ontario, London, Canada. He is also the Director of Dentistry at the South-western Regional Center and has a private practice limited to endodontics in London.

The Serena Merck Memorial Award

for Innovation and Dedication in Practice 2002

Purpose of the Award The Serena Merck Memorial Award is given annually to an exceptional individual who has demonstrated long-term, selfless dedication and compassion in the care or service to children who have retardation and significant mental health problems. Mrs. Merck recognized the critical importance of what quality day-to-day care provided by committed individuals can make to children with cognitive and behavioral disabilities. The John Merck Fund has established this major, national award to honor her long-standing commitment to this field, and to call attention to the invaluable role caring individuals play in it.

Criteria for Selection of the Awardee Prospective awardees should meet one of the following categories: (1) Provides, as an employee or volunteer, services for children who have mental retardation and significant mental health problems. (2) Demonstrates long-standing commitment and innovative care of this population which has positively affected their quality of life and/or life opportunities.

Submission Guidelines Organizational entities may nominate prospective awardees. One nomination per organization is permitted, although multi-service organizations may submit one nomination from more than one service unit. No self-nominations are acceptable. Only organizations serving children with mental retardation and significant mental health problems are eligible to nominate an individual. A 500-word summary of the reason the candidate is nominated, length of service in the field, and a description of the person's impact on children with mental retardation and significant mental health problems is required. At least two, but no more than five, accompanying letters of reference from individuals well qualified to evaluate the candidate's suitability for the award should be provided.

Nominations should be mailed before August 1, 2002, to:
Mr. Frank Hatch, The John Merck Fund,
11 Beacon Street, Suite 1230, Boston, MA 02108

Award A $5,000 cash award and plaque will be presented to the awardee at the 19th Annual National Association for the Dually Diagnosed (NADD) Conference held October 23–26, in Denver, Colorado. The awardee's travel expenses to the conference will also be covered.

Circle #69 or visit www.eparent.com/adinfo

Special Report | Part II: The Decision and The Battle

by Lauren Agoratus

The Center for DISCOVERY

INFORMING

EMPOWERING

AND KEEPING PARENTS INVOLVED

Sometimes battle lines are drawn when parents of children with special needs fail to get the services to which they are entitled. Parents who overcame the numerous obstacles that confronted them share their strategies and successes.

Working within the system but being aware of the fact that persistence pays off is often the key to success. However, to do this, many parents need to cast aside prior notions of politeness and deference in order to obtain needed services for their children.

Early on, parents are buffeted by the trauma of discovering, the special circumstances of their child. Physicians, healthcare professionals, social services providers and family are all offering advice, comfort and support. To many parents, the entire process is overwhelming.

They sometimes develop a sense of courtesy and dependence on professionals that may not continue to be in the best interests of their child.

Starting Out

The support and experience provided by other parents of children with disabilities are often vital for those who are just starting out. Pat Tavis of New Jersey has two sons, both of whom have special needs. Her son Ryan, 10, has autism and her other son Christian, 5, has Asperger syndrome (pervasive developmental disorder). From the time Ryan was diagnosed until he reached the age of three, he was eligible for and received early intervention services. When Ryan completed early intervention, Pat's school district then offered a half-day preschool disabled program for him.

Pat knew a half-day would not be enough to help her son, but had to learn how to advocate for what he needed. By joining various support groups where she networked with other parents, she learned about her son's rights. Pat presented the school district with reports from the early intervention teacher recommending a full day. With those recommendations she was able to fight for a full day program at the Developmental Learning Center in New Jersey. She later did the same for Christian by getting reports from his teacher as well as from his speech and occupational therapists. Pat wants other parents to know that there are choices. If school personnel are unable to write a letter that disagrees with the position taken by the Committee on Special Education (CSE) an evaluation and recommendation by an independent educator or clinician may be necessary.

Getting the Right Support

When Monica Ramos of New York realized that her son Jesse wasn't progressing in school, she took a closer look at his Individualized Education Plan (IEP). She found that the school hadn't updated his goals annually. Over four years, they had merely used "white-out" on the date instead of updating it properly.

Jesse, who is blind and has autism, mental retardation, cerebral palsy, hypotonia and uses a wheelchair, wasn't getting the attention he needed. In a class of twelve with a teacher and aides, Jesse was not provided with a one-on-one assistant and was given only thirty minutes of therapy twice a week.

Monica says she couldn't believe she had trusted the system that so miserably

continued on page 88

THIS SERIES IS MADE POSSIBLE BY AN UNRESTRICTED EDUCATIONAL GRANT FROM THE INTERNATIONAL FAMILY INSTITUTE AT THE CENTER FOR DISCOVERY IN HARRIS, NEW YORK. WWW.DISCOVERYIFI.ORG - WWW.THECENTERFORDISCOVERY.ORG

Strategies

Knowledge comes from attending meetings/conferences, support groups, learning resource centers, and disability specific organizations.

Many parents mentioned other parents as a primary source of information as well as matching groups such as Parent to Parent, as frequently researched on the Internet.

Recording IEP meetings and bringing an advocate along or getting information from a Parent Training and Information Center was cited as key to success.

One inventive parent sent a picture of her hospitalized baby girl on pink paper to medical billers with the message, "Hi, my name is Lizzie. My Mommy and Daddy are really busy taking care of me right now, so I would really appreciate it if you could straighten out this misunderstanding. Here is a copy of all my insurance information. Thanks!" This saved the parents many phone calls and letters and made it "real" by showing that the piece of paper represented a person.

Other options are special classes, special schools, non-public school or instructional venues.

Ultimately, it is the parent's responsibility to insure that the child is making progress and is receiving the services of sufficient quality. The best way of insuring this is maintaining a strong presence within the school system and to bring to bear attorneys, specialists and advocates to make things happen for the children.

BEST COPY AVAILABLE

continued from page 87

failed her son. She visited his class and found several problems. The teacher was pointing to pictures throughout the lesson, pictures that Jesse couldn't see. The teacher would also try inappropriate approaches, such as "This is how Tuesday feels."

"You can't feel a day of the week!" exclaims Monica. She noticed that the classroom aides, not the students, were doing the art project and saw one actually stop a child who wanted to try it by himself.

The aides were also reading and eating during class. Monica wanted better placement for her son, even if it meant placement outside the school district or in a residential setting. When she appealed formally to the school district, however, she was told "private or residential placement is not something we do," though this is a violation of IDEA, which is a federal law that covers all school districts.

Monica began doing her own research to look for the best placement for her child. She found a residential facility that would meet Jesse's needs. "I met the teachers, the program is good, and they work well with children who have vision problems," Monica said. Residential placement was not a decision she made without anguish. Initially she argued with her own mother over her decision, finally convincing her mother after a tour of the facility.

Then she went about dealing with the school district. At first, officials informed her that she had to prove they weren't providing Jesse with an appropriate education. Monica hired a lawyer who discovered, in addition to the violation of Jesse's right to an appropriate education, that the school had not followed procedure to provide Monica with a parent liaison at her meetings as required. Monica also worked with a New York parent advocacy group who appointed a caseworker to attend the IEP meetings with her and commissioned an impartial overseer to evaluate his program and assess his growth.

Thanks to Monica's efforts, an education specialist, and the intervention of an attorney, the Board of Education approved the placement. Jesse now attends the Center for Discovery, a residential facility in upstate New York. Monica advises other parents to check their child's IEP carefully, read about parents' rights and get an advocate and/or lawyer. Monica visits with Jesse each weekend and he comes home in the summer. She is confident she made the right choice for her son and notes his improvement. "Jesse is feeding himself for the first time. He can deal with noise and with people. And he's happier now."

Many other parents of children with special needs have discovered that they, too, have had to become advocates for their children.

Larry Greenstein describes his own experiences with his now 10-year-old son Kevin. The boy had birth trauma with prolonged episodes of hypoxia that resulted in cerebral palsy. At a young age Kevin presented like a kid with a pervasive developmental disorder.

When Kevin was two, Larry and his wife, Dr. Star Anthony, discovered Dr. Stanley Greenspan, a highly respected authority on developmental disorders who is a professor of psychiatry, behavioral sciences, and pediatrics at George Washington University Medical School. Larry describes Kevin's progress and his efforts below.

With his help we set up a "Floor Time" program at home. Floor Time is a way of addressing a child's developmental changes with an emphasis on following the child's lead and playing at their developmental level. Kevin also attended a pre-school recommended by the Committee on Pre-School Education.

We tried to train the preschool in the Floor Time program, but without success. So we removed Kevin from the school and placed him in a standard half-day pre-school with an aide that we paid for to help him with socialization. The other half of the day we used the Floor time program at home. The district provided a minimal amount of related services for Kevin at home, but not in sufficient quantity to be effective. They did not agree to any aide time or teacher time.

(Many parents can not afford to do what Larry did. They must continue to focus on getting support from local and state agencies.)

When the CSE met to handle Kevin's placement once he turned five, they recommended a special school. We felt that there would not be appropriate children for Kevin to model and that his social development would be stunted. We filed for Due Process hearings on both the CPSE and CSE recommendations.

Children share smiles and hugs despite their parents worries.

Our strategy was multifaceted. As a first step, we retained an attorney who told us that parents rarely win and we should expect to have to go to Impartial Hearing to get anywhere. We started calling all of the Board of Education members explaining our case and asking for their help. We also asked our local political representatives to get involved. One County legislator met with the Superintendent on our behalf and agreed to send a representative to our CSE meeting "just to observe."

At the same time we went very public. After getting copies of the district legal bills under Freedom of Information Law, (FOIL) we wrote letters to the editor of our local papers explaining the situation. We followed that up with letters from friends who wrote to the editor in response to our letters. This caused a constant stream of comment.

Once we got our story out and showed how much taxpayer money was being squandered to deny Kevin an education that is cheaper than an out-of-district placement, it was just a matter of time. The Board replaced their attorney during our Impartial Hearing. The new attorney was much more amenable to a settlement and we went that route.

Kevin is now in a mainstream third grade class. He still has many issues and struggles, but everyone in the district admits that he belongs there. The district uses Kevin as an example of how we can return kids to our schools and we are trying to bring back more kids.

Kevin won, and so did his classmates, who are learning that you can be "different" and still be a friend. Teachers are finding that teaching challenging children keeps them sharp. The parents are discovering that Special Education benefits all children.

Larry is just ending a four year stint as co-president of our local Special Ed PTA, and has spoken to many families who are involved in various disputes. The advice that he gives them is generally along these lines:

1) Don't be ashamed of your child's problems. Look for help wherever you can find it.
2) It is more important to be respected than to be liked. Know your stuff and don't back down.
3) Ask for the stars when you only want the moon.
4) Everyone needs to feel like they've won. Leave room for compromise.
5) Don't get personal. When you win, these will be the people working with your child. You will need them as allies.
6) Get involved. Be an active parent. Not only does it build support among other parents, but also among the staff, which can be invaluable.

Often times, parents are flooded with insurance bills and additional costs. The arrival of mail is often a time of heartache and despair. For many parents, the sheer effort associated with completing forms, obtaining medical records, and tracking down files lost among unseen medical paper pushers can cause extreme stress.

Lauren Agoratus talks about her own experiences in this medical and support services environment. Lauren is the parent of a child with Asperger syndrome and kidney disease. She serves as the NJ State and Region II (NJ, NY, VI, PR) Coordinator for Family Voices, a national advocacy group for children with special health care needs.

The first red flag was raised when our insurance company denied my daughter's claim for physical therapy despite that fact that is listed as a covered service in the employee handbook, a fact which we verified by phone. I fought them for a year and a half and won, only to have a claim denied for occupational therapy the next year, which took another year and a half to appeal and win.

The second flag popped up when my daughter's doctors said it was okay for her – a medically fragile, homebound child – to begin to attend school at age six and a half. Our school district wanted to bus her to a full day program for children with developmental delays that is forty-five minutes away. We decided to move so that our daughter would be in a better district.

The red flags were warnings signaling my need to become an advocate for my daughter. To be an advocate for your child means pushing to get what your child needs, oftentimes what he or she is entitled to under the law. The principal part of being an advocate is educating yourself about your child's rights and being assertive in protecting them. I have found myself constantly struggling against medical and educa-

continued on page 108

continued from page 107

tional systems that were supposed to help my family. I have also found that I am not alone.

Struggles

Sheila Donnelly says that her biggest struggles are over bills from medical providers. Her son Nathanel has traumatic brain injury. Nathanel has coverage from three health insurance sources, including Medicaid, for all the services he needs. Yet no matter how hard Sheila tries to make sure all healthcare providers who treat him have all of his insurance information and copies of his cards, because of medical billing errors she still gets bills for the balance due. The providers either don't bill the insurance carriers in the correct order, or they don't bill insurance at all. Sheila says medical bills arrive in her mailbox on a daily basis.

RESOURCES

Education Law

Parent Advocacy Coalition for Educational Rights Center (PACER)
(952) 838-9000; PACER Parent Training and Information Centers (888) 248-0822;
http://www.taalliance.org;
e-mail: alliance@taalliance.org
Assistance and materials for parents and professionals in securing a free and public education for all children.

Wrightslaw
(877) 529-4332;
http://www.wrightslaw.com;
e-mail: webmaster@wrightslaw.com
A free web site offering extensive legal information about rights and protections regarding special education, and a source for ordering the books From Emotions to Advocacy-The Special Education Survival Guide and Special Education Law

Healthcare coverage

Family Voices
(888) 835-5669;
http://www.familyvoices.org ;
e-mail: kidshealth@familyvoices.org
Family Voices is a national grassroots organization. Coordinators in each state provide information on SSI (Supplemental Security Income), Medicaid, and how to appeal insurance claims.

Families USA
(202)628-3030;
http://www.familiesusa.org;
e-mail: info@familiesusa.org
A not-for-profit organization dedicated to high-quality, affordable health care and long-term care.

National Information Center for Children and Youth with Disabilities (NICHCY)
(800) 695-0285;
http://www.nichcy.org
Provides free information on a wide variety of disabilities and helps to identify educational programs and services.

Emotional Support

Beach Center on Families and Disability
(785) 864-7600;
http://www.beachcenter.org
e-mail: beach@dole.lsi.ukans.edu
Distributes family-friendly products including manuals, booklets and videotapes. Web site links to statewide Parent-to-Parent organizations that match parents seeking information and support with experienced parents of children with similar disabilities.

The Center for Discovery Box 840
Benmosche Road Harris, New York 12742
(845) 794-1400
http://www.thecenterfordiscovery.org
http://www.discoveryifi.org
A private, not-for-profit prep school that provides educational, clinical and residential programs and comprehensive on-site evaluations for children and adults with significant disabilities. The International Family Institute offers information, assistance and support to educational professionals and families of children with disabilities.

BEST COPY AVAILABLE

Successes

Donene Fiest of North Dakota is the mother of two sons; Tyler, who has attention deficit/hyperactivity disorder and learning disabilities, and Zach, who has hearing impairment. Donene has found that there is an obvious difference between disabilities that are hidden and those that can be seen. Misunderstandings arise from the "invisible" disabilities. Donene is also an advocate for others, a position she finds less taxing than advocating on her own children's behalf. "For my own, the battle is close to my heart; it is personal and can be absorbed into a parent's soul," she says. Donene found that the bottom line is communication so that some middle ground can be reached. In order for that to happen, parents and professionals cannot make assumptions, or the partnership will dissolve. "If everyone comes to the table with their own agenda – therapy, school, providers – that can be difficult to overcome." Donene has found that advocating for children is one of the most rewarding experiences she has had.

Rachael Cocozza of New Jersey successfully advocated for her son Adam, 8, who has autism. She had assistance from Adam's grandmother, who is an educator at a special school. Rachael's dilemma was finding an appropriate school program. She researched the best programs and found there were none in her school district that would meet Adam's needs. Adam started in a preschool program that was only two and a half hours per day. Rachel threatened to go to Due Process for an appropriate placement.

Rights under IDEA

The Individuals with Disabilities Education Act (IDEA) is a federal law. Some of the key components state that all children are entitled to a "free appropriate public education." This includes special education and related services (such as, but not limited to speech, physical and occupational therapy) provided at public expense. Education must be done in the "least restrictive environment"; "Children with disabilities are educated with children who are not disabled and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

Under the Due Process clause of the Fourteenth Amendment, states may not deprive any person of life, liberty, or property without due process of law. Protected property rights are created by such sources as state statutes granting persons certain benefits. The Supreme Court has held that students have a property interest in education that required minimal Due Process protections.

Threats alone can be counterproductive, but if parents have exhausted all other avenues without success, when threats are made parents must be prepared to follow through. In Rachel's case, rather than face a lawsuit, the school immediately gave her options. Adam was able to attend the Search Day School in New Jersey that uses an intervention called "pivotal response." The original goal was to bring Adam back into district for kindergarten. Rachael was able to arrange a split between the preschool program and the special program, resulting in a full day for Adam. At age six, Adam attended half-day kindergarten. Since then Adam has been attending public school for first and second grade. His program involves team teaching in an "inclusion" class with a special education teacher. These days, Adam doesn't even need an aide.

Ruth Moore of Oklahoma advocated for her own children and then became an advocate for others. Between them, her children—Melissa, Dean, Robert, D'Monique and Phoebie – have a range of neurological and psychological disabilities. Ruth usually had positive dealings with her school district, with the exception of one principal who made it difficult to obtain services. One of her daughters was hospitalized for seven months but now, with appropriate supports, she is able to split her day between regular and special education classes. Another child's challenging behaviors were addressed with support from the law enforcement community through a violence prevention program along with an individualized curriculum, a reduced school day, and a summer employment program to help with social skills.

Ruth encountered problems with the school system, however, when it came to her son Dean. She felt Dean was not being given the services he needed and requested that his progress in school be evaluated before his next IEP was written. Until the evaluation was completed, she requested an interim plan under Section 504 of the Americans with Disabilities Act (ADA) which was the first federal law to prohibit discrimination based on disability.

But Dean's school did not implement the 504 plan and Dean began to fail in school. When the principal put the IEP process on hold as a last resort, Ruth referred her to the federal IDEA law and hired a paralegal to write a complaint letter to the state's Department of Education. The school quickly decided they should begin the evaluation. Ruth is currently undergoing mediation with the district, but in the meantime they are following the 504 recommendations and Dean's academic progress has improved.

Finding the Way

The parental instinct to protect a child is kicked into high gear when that child has special needs. Parents find themselves grappling with the educational, medical and legal systems in a struggle to provide a full and rewarding life in spite of a child's disabilities.

It is easy to lose heart when the systems that are expected to provide direction and assistance become antagonists in a battle for dignity and human rights. But by banding together and reaching out to the community of others who have traveled the way before them, some parents, enlisting the aid of trained, experienced experts such as attorneys or advocates, find an enriched sense of meaning and a way to turn those struggles into strategies for success. And, depending on each family's circumstances, success will mean different things to each of them. However, each family needs to know that all along the continuum from total inclusion to residential placement, if it makes sense for their child and their family, it is the right way to go. **EP**

Lauren is also the NJ Caregiver Community Action Network representative for the National Family Caregivers Association and was recently appointed by the governor to serve on the State Interagency Coordinating Council.

Support Groups

National Self-Help Clearinghouse
(212) 817-1822;
http://www.selfhelpweb.org;
e-mail: info@selfhelpweb.orG
A not-for-profit organization that facilitates access to self-help groups the awareness of the importance of mutual support.

BEST COPY AVAILABLE

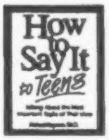
WWW.EPLIBRARY.COM

EP Exceptional Parent LIBRARY

THE SPECIAL NEEDS BOOKSTORE

PARENTING

How to Say It to Your Kids
The Right Words to Solve Problems, Soothe Feelings, and Teach Values
Dr. Paul Coleman
This insightful and beautiful parenting manual is filled with a wealth of information that you can immediately use to transform your children's lives. It accurately predicts the traps many fall into and offers practical and sensible advice for dealing with many issues parents face when raising any child.
PH1773PA **$14.00**



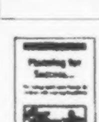
How to Say It to Teens
Talking About the Most Important Topics of Their Lives
Richard Heyman, Ed.D
If men are from Mars and women are from Venus, then teenagers are from an entirely different universe. Here you'll discover surprisingly easy ways to keep the lines of communication open throughout your child's turbulent adolescent years.
PH1889PA **$16.00**

SPECIAL KIDS NEED SPECIAL PARENTS

Special Kids Need Special Parents
A Resource for Parents of Children with Special Needs
Judith Loseff Lavin
Parents of children with special needs face unique emotional and practical challenges every day. These issues are seldom fully addressed by the medical community—an parents' most compelling questions remain unanswered. The author draws upon interviews with health care professionals, nationally recognized authorities and families of special need children to give readers the advice, encouragement and comfort they crave.
GP6622PA **$13.95**

The Parent to Parent Handbook
Connecting Families of Children with Special Needs
Betsy Santelli, Florene Steward Poyadue, Jane Leora Young
As a parent you have lots of questions, If you child has a disability you probably have even more. One of the best ways to find answers to your questions is through "Parent to Parent Programs". Written by two mothers that have been there this book will explain how these valuable programs work and how they can give you the help you need.
PB4979GN **$29.95**

IEP



Planning For Success
The College Application Process for Students With Learning Disabilities
The college admission process can be a confusing and overwhelming experience for students with learning disabilities and their families. This comprehensive video enables you to see the college application process from the very beginning. It shows early planning, college visits, the essays, and how to choose the best school for you.
LD201LD **$79.95**

COMING SOON!!

EPLibrary Book Club
Learn more by sending
us an email at
eplibrary@aol.com
with UPDATE in the subject.

The Complete IEP Guide
How to Advocate for Your Special ED Child
Lawrence M. Seigel
A comprehensive step by step guide through the entire IEP process that provides encouragement to the reader as it takes a complicated process and makes it easier to understand. Provides instructions, suggestions, strategies, resources, forms and much more.
NL0015E **$24.95**

HOW TO WRITE AN I.E.P
NEW
THIRD EDITION

How To Write An IEP
John Arena
Parents, teachers, administrators and others involved in IEP preparation and implementation will profit from this brief, easy-to-use, handbook. This text will serve as an invaluable reference for making sure all factors of consequence are given the consideration they require.
AT2005E **$19.95**

FOR YOUNG PEOPLE

Never Sell Yourself Short
Stephanie Riggs
with photographs by Bill Youmans
Josh is a stereotypical teenage boy. He plays sports, spends time with his friends, and can't wait to drive. Josh is also short statured, and in this inspiring essay he talks about life in a world that is scaled for people much taller than he. His story is inspirational for everyone with obstacles to overcome in order to chase their dreams.
AW5630YP **$15.95**

Allie Learns About Alzheimer's Disease
A Family Story About Love, Patience, and Acceptance
Kim Gosselin
with illustrations by Tom Dineen
This touching story about a girl and her relationship with her grandmother who suffers from Alzheimer's Disease is an excellent way for parents to introduce such difficult topics such as family healthcare to their children.
JB3159AZ **$14.95**

Taking Cystic Fibrosis to School
Cynthia S. Henry
with illustrations by Tom Dineen
This heartfelt children's story helps to explain for kids and their parents what cystic fibrosis is, how it is treated, and what activities children can participate in with others.
JJ3094YP **$11.95**

EPILEPSY

Epilepsy: The Facts
Second Edition
Anthony Hopkins and Richard Appleton
This excellent book is designed to present the facts about every aspect of epilepsy in a clear and consice manner. Written by a neurologist, it presents a clear definition of epilepsy, the different types of seizures associated with the disorder, the medical and surgical therapies used, as well as providing practical points on living with epilepsy.
OU5489EP **$19.95**

Brain Development and Epilepsy
Philip A. Schwartzkroin, Solomon L. Mosh, et al.
This integrated volume applies the emerging concepts in development neurobiology to an understanding of the origins of the epilepsies of childhood. This practical text covers age specific epilepsies, experimental approaches and therapies, and the integration of such knowledge to help formulate a plan to assist in effective treatment for these often devastating syndromes.
OU8462EP **$59.95**

Partial Seizure Disorders

Partial Seizure Disorders
Help for Patients and Families
Mitzi Waltz
A no-nonsense step by step book that offers an approach to partial seizure disorders based on the latest medical research as well as personal experiences of people with the disorders. Inside you will learn how to obtain an accurate and complete diagnosis, how to cope with the diagnosis, and what treatment options are available.
OA0033EP **$19.95**

ASPERGER SYNDROME

Beyond the Wall
NEW

Beyond The Wall
Personal Experiences with Autism and Asperger
Stephen Shore
This book provides an interesting, well-written, and insightful autobiographical account of the life of a person with high-functioning autism/Asperger Syndrome. In a way that only one who has been there can, the author offers valuable information that will be of assistance to anyone coping with Asperger Syndrome.
AA1486AS **$19.95**

Just This Side of Normal
Glimpses into Life with Autism
Elizabeth King Gerlach
This mothers story captures the challenges of raising a child with autism. She can touch her son, Nicky, but not connect with him; hear but not understand his chanted phrases. Yet she embraces life-the joy and sorrow, hope and despair, frustrations and fear without flinching. This story testifies to the power of a heart that has broken wide open.
FL101AT **$19.95**

Pretending to be Normal
Living with Asperger's Syndrome
Liane Holliday Willey
This book peers under the umbrella of autism and looks at AS, a relatively new less debilitating autism-related diagnosis. Although first discovered in 1944, not much information has become available until the early 1990s with the establishment of a diagnostic criteria set forth by Gillberg and Gillberg. Here is shown that AS individuals are a bright thread in the tapestry of life and our civilization would be extremely dull and sterile if we did not have and treasure individuals with the condition.
TF250AS **$17.95**

PHYSICAL DISABILITY

Nick Joins In
Joe Lasker
A free, appropriate public education is guaranteed for all handicapped children and whenever possible, they will be educated alongside non-handicapped children, a practice known as "mainstreaming". This book may help over come child's apprehension.
AW1180D **$14.95**

Yes You Can !!!
Go Beyond Physical Adversity and Live Life to its Fullest
Janis Deitz, PhD
Embracing the premise that life should be lived to its fullest, disability or not, this book presents ways for anyone to weather challenges, illnesses, or disabilities. An energetic and zest-filled read, the book will leave you with a "can-do" attitude.
DE948XPD **$15.95**

BEHAVIOR

The Anti-Bullying Handbook
Keith Sullivan
Written for Parents, teachers, administrators, counselors, therapists this resource can help us to understand what bullying is and how to arrest it or to prevent it. Part I gives a clear overview of what we understand about bullying and Part II provides information on how to deal with with bullying.
OU3884BE **$19.95**

AUTISM

Autism and the New Law
Resources for Treatment, Hope for Cure
NARRATED BY: Anthony Edwards
This 30-minute video is designed to help parents, educators, and health care professionals better understand Autism or similar diagnosis such as PDD and Asperger Syndrome. Learn about the components of The Advancement of Pediatric Autism Research Act and how it affects the lives of you, your child, and your family.
EV6882AT **$49.95**

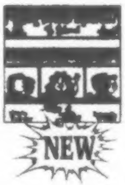
Fragile Success
Ten Autistic Children, Childhood to Adulthood
Virginia Walker Sperry, M.A.
In this book you will get a view of autism in all its variations as the author, a former teacher, traces the lives of her students over 30 years These true case histories provide exceptional insight into the mystery and diversity of autism.
PB4587AT **$24.95**

A Work In Progress
Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism
Ron Leaf and John McEachin
A superb collection of ideas and programs for building skills as well as strategies for dealing with challenging behaviors. It is a comprehensive guide presented in user-friendly language so parents and professionals can easily understand and use this valuable resource.
DR6600AT **$42.95**

Raising a Child with Autism
A Guide to Applied Behavior Analysis for Parents
Shira Richman
Applied Behavior Analysis (ABA) is increasingly recognized as a highly effective way of helping children with autistic spectrum disorders. The author explains how parents can adapt the practical techniques used in ABA for use at home, providing tips and advice for families and parents.
TF9106AT **$19.95**

TOURETTE SYNDROME

Tourette Syndrome: Finding Answers and Getting Help
Mitzie Waltz
Tourette's syndrome is a neurological disorder usually diagnosed in childhood. It is characterized by tics; physical jerks and involuntary vocalizations. Some people with Tourette's also have other brain-based disorders, particularly ADHD or OCD. This book is designed to help you: Secure accurate and complete diagnosis; Live with Tourette's in the family; Understand medical interventions; Obtain appropriate medical care from an existing health plan; Find resources and much more.
[illegible] **$24.95**



Taking Tourette Syndrome to School
Tira Krueger with illustrations by Tom Dineen
This excellent children's story about a girl with Tourette Syndrome is essential for any family that wishes to understand what the disorder is, where it comes from, and what impact it has on the child's life.
JB3124TS **$11.95**

Children With Tourette Syndrome
A Parents' Guide
Edited by T. Haerle
Written by a team of professionals and parents, this book covers medical, educational, legal, family life, daily care, and emotional issues.
WB0160D **$14.95**

ATTENTION DEFICIT

Distant Drums, Different Drummers
A guide for young people with ADHD
Barbara D. Ingersoll, Ph. D.
A view that offers children and adolescents struggling with ADHD the opportunity to see themselves in a positive light due to their penchant for novelty and exploration and boundless energy.
CP1008AD **$15.95**

Teaching Teens with ADD and ADHD
NEW

Teaching Teens with ADD and ADHD
A Quick Reference Guide for Teachers and Parents
Chris A. Zeigler Dendy, M.S.
Recognizing the pivotal role teachers play in the long term success of their students, this book provides information via 75 concise summaries on key issues related to attention deficit disorder. Beyond the thorough review of the basics, this guide also illustrates how the characteristics of the disorder can affect academic performance while presenting strategies interventions and tips to make teacher's jobs easier.
WB7208AD **$18.95**

RESOURCES

Exceptional Parent
A Comprehensive Listing of National Resources for Specific Disabilities; Disability Matching Resources: Parent to Parent Programs; Association of University Centers on Disabilities: Alliance for Technology Access Center and State Assistive Technology Programs; National Directory of Vocational Rehabilitation Programs; Comprehensive listing of new and ever popular editions of special need books and videos in EPLibrary.com; Directory of Canadian Resources Plus much much more.
EP620EP **$19.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: **EP**, Dept. EP0702, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call **800•535•1910**

QTY.	ITEM#	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

These prices are subject to change without notice.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

Name ____________________
Address ____________________
City ____________________ State __________ Zip __________
Telephone ____________________ E-Mail ____________________
I have enclosed my check payable to Exceptional Parent or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover
Account Number: ____-____-____-____ Exp. Date ____/____
Signature ____________________

Circle #200

familiar faces

STEVEN

Steven Matthew Carreno, 2, and sister **Katelyn**, 11 months., have a special bond. Steven was born with the umbilical chord wrapped around his neck, which resulted in severe brain damage. He has Cerebral palsy, seizures, cortical blindness and a feeding tube. He enjoys music, bright lights, cuddling and being adored by Katelyn!

JULIA

Pictured are **Julia Murphy**, 16, and her sister **Erin**, 12, who has Rett syndrome (a rare neurological disorder). In this snapshot the girls are enjoying patriotic holiday decorations at a local plaza. Erin attends the Carusi Middle School in Cherry Hill, NJ,where she participates in seventh grade activities.

MICHAEL

Michael Arechavala, 3, loves playing with his brother, Kevin, 9, and sister, Michelle, 5. Michael has Down syndrome, and attends a fully inclusive preschool all week where he receives OT, PT and speech therapy. He enjoys going to the playground, eating ice cream and hanging out at the beach.

NATALIE

From the moment that **Chip** (right) met **Natalie Aurelio**, 11, he knew that she was someone special. No matter who she meets, instant bonds of friendship and support are created that bring joy to Natalie's life and to the lives of those around her. Natalie is fighting a rare, degenerative brain disorder called Batten disease. She lives with her parents Liz and Dave, her 13-year-old brother Nicholas and her canine pal, Chip.

AMANDA

Amanda M. Van Aken, 9, has a smile a mile wide. Amanda has Cerebral palsy, is non-verbal, communicates with a communication board and has recently learned how to walk on her own! She enjoys listening to music, swimming and going to school. Amanda lives with her mom Laura Naccarato in Brooklyn, NY, and loves to play with her best friend in the world, Sandra Lane.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (Exceptional Parent), 65 E. Route 4, River Edge, NJ 07661. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

Information and support for the special needs community

PARENTS ○ FAMILIES ○ PHYSICIANS ○ PROFESSIONALS

SYMBOL OF EXCELLENCE EP CONTENT • COMMUNITY • CARE

Exceptional Parent Magazine

Welcome Resources Technology Edu/Toys Healthcare Subscribe

eparent.com

New! Visit the EP Web site, EParent.com, and discover…

TOYS—The new eToys Web site (www.etoys.com) teams with EP's Web site, EParent.com (www.eparent.com) to offer ideas, information and imaginative toys for families with kids who have special needs. When parents, teachers or caregivers shop at eToys and visit the co-branded EParent.com site, they'll find hand picked toys and games, plus featured articles from EP Magazine. The site also features direct links to the EParent.com shop at eToys, and eToys products recommended by experts or reviewed by organizations chosen by EP Magazine.

EDUCATION—EParent.com's newly-constructed Education channel (EDU/TOYS tab) yields a wealth of current articles on topics such as IDEA, IEPs, assistive technology, transitioning and inclusion. These are supplemented by a growing directory of schools, camps & residences, which can be found in the "Directories" link of the "Resources" channel.

ON-LINE ARCHIVES—Now, EParent.com users can preform keyword searches through our on-line archives and purchase articles which have appeared, as far back as in the eighties, in EP Magazine (recipient of awards from Folio:The Magazine for Magazine Management, Easter Seals, Consumer Healthcare Group). These include classic pieces on such subjects as early childhood, rare disorders, technology, education, medical research update, transitioning, travel, all of which have distinguished EP Magazine through the years

MORE TO COME IN 2002—You can also click through our EP Library (www.eplibrary.com) which contains books, videos and software encompassing almost 50 specific and general categories, with more than 650 titles. Of course, we will continue to refresh and improve EParent.com in 2002, and look forward to receiving your comments and suggestions. Log on and find out what we are all about!

EP Exceptional Parent

BOBBY APPROVED
Click here for our Text only site.

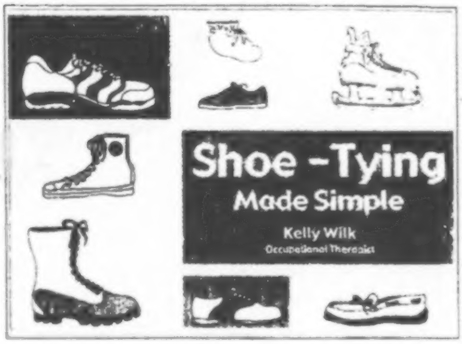
NOW SUBSCRIBE ON-LINE

National Resource Directory

WWW.EPLIBRARY.COM
EP LIBRARY
THE SPECIAL NEEDS BOOKSTORE

www.eparent.com

new products



SHOE-TYING MADE SIMPLE!

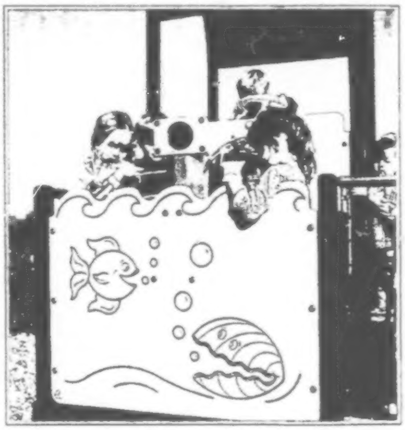
Shoe-tying Made Simple is a tutorial aid developed to assist children with disabilities learning how to tie their shoes. The kit includes color-coded laces, a full color standup instruction manual and instructions for both left and right-handed children. Each step is presented in 3 different ways. Full-color pictures are provided for the visual learner, a rhyming story helps the auditory learner and tactile kinesthetic cues assist the hands-on learner.

Junction of Occupational Therapy Function, 447 Ibis Way, Naples, FL 34110, 941-777-4009,
E-mail: Kelly@junctionof-ot-function.com, URL Web Site: http://www.junctionof-ot-function.com

SNAKEY®

SNAKEY® is a plush puppet designed to assist children with disabilities in the development of fine motor skills. It's seven detachable color-coded segments each joined by a different type of fastener, providing children with the skills to use buttons, snaps, clips, zippers, plastic buckles and Velcro®. SNAKEY® is over five feet long and machine washable.

Fi-Mo Toys, 2509-2045 Lakeshore Blvd. West, Etobicoke, Ontario, M8V 2Z6, 866-800-6312,
E-mail: info@fi-motoys.com, URL Web Site: http://www.fi-motoys.com



PERISCOPE PANEL

The Periscope Panel is a wheelchair accessible playground activity panel. This height adjustable panel is constructed from three-quarter inch thick high-density, U.V., stabilized, colorfast polyethylene material called Permalene®. The periscope can rotate from side to side and tilt forward thirty degrees. It is equipped with an octagonal tube containing stainless steel mirrors and accommodates children from two to twelve years of age.

Landscape Structures Inc., 601 7th Street South, PO Box 198
Delano, MN 55328-0198, 888-4FUNLSI, 763-972-3391, 763-972-3185 fax
E-Mail: info@playlsi.com, URL Website: http://www.playlsi.com

Lets Have Fun
An Exercise Program For People With Special Disabilities

LETS HAVE FUN

Lets Have Fun is an exercise video program designed for people with disabilities. It starts with a warm up that stretches all muscles and increases heart rate. An aerobic segment features low-impact exercises with visuals to help stimulate the imagination, while a cool down helps to increase flexibility and return the heart rate to normal. The Lets Have Fun video exercise program also includes a free style dance segment to increase motivation.

Healthy All Over Ltd, PO Box 953, Commack, NY 11725
631-864-9173 voice/fax, E-mail: laura@healthyltd.com, URL Website: http://www.healthyltd.com

---

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

Now he has a place for everything like everyone else.

It's unique ball-joint movements and sturdy support put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, and pencils. And when it's time for transfers, the entire desktop swings down to the side.

1-800-4 MYDESC
www.mydesc.com
Santa Clara, CA 95056

Circle #1

WOODBINE HOUSE CATALOG

NEW BOOKS on Down syndrome, autism, and gluten-free cooking!

Publisher of the Special Needs Collection
WOODBINE HOUSE
Gluten-Free Kid-Friendly Cookbook
Down Syndrome and Nutrition
Inclusion Story... with an Iguana!
New Workbook enables independent writing
Autism and Parenting
www.woodbinehouse.com

The new Fall 2002 Woodbine House catalog features our **Special-Needs Collection**, 63 books on a wide variety of disability topics for parents, children, teachers, therapists, and health care providers.

**For a FREE catalog, contact:
Woodbine House at 800-843-7323
www.woodbinehouse.com**

Circle #2

freedom
what is your definition?
call us today!

1.800.661.9915
www.freedomconcepts.com

Circle #3

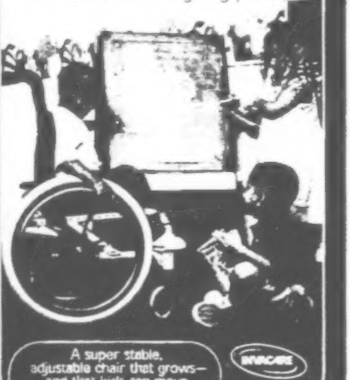
EXCEPTIONAL PARENT

Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores all across America, every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books. $4.95 Cover Price.

Circle #4

INTRODUCING
the Invacare® Top End® Terminator® Jr. for kids who are going places!



A super stable, adjustable chair that grows—and that kids can move all by themselves.

INVACARE
Yes, you can.

2002 Invacare Corporation. Invacare, Terminator, Top End and Yes, you can. are trademarks of Invacare Corporation.

Circle #5

Natural Access™

Expand your horizons with the Landeez All-Terrain Wheelchair!

Rolls easily over sand, snow, gravel, and uneven terrain, so you can enjoy the outdoors

For more info 800-411-7789 or visit
www.landeez.com

Circle #6

MARKETPLACE

ACCESSIBLE TRAVEL

Disney Area Villa rentals
4 miles from Disney World. 3/2 (sleeps 8) Accessible Resort Villa. All your Special Needs, Scooters, Oxygen, Cruises & Dialysis Program by www.medicaltravel.org
Call 1-800-778-7953.

ATTORNEY

Attorney Richard Gottesman
(800)295-1107
gottesman@law.com
Cerebral Palsy, Brachial Plexus/Erb's Palsy and Childbirth Injuries

BEACH WHEELCHAIR

Affordable Independence in the Great Outdoors!

The Features Make All the Difference!

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure

BEACH SWIMMING POOL

TIRALO™
FLOATING BEACH CHAIR

Call now: (360) 796-3197

www.oasisllc.com

To Advertise in
Marketplace Contact:
Barbara Nastro
Tel: (908) 534-6366
Fax: (908) 534-6941

DIAPERS

DIAPERAPS®
Since 1984
Youth Swim Diapers
1-800-477-3424
www.diaperaps.com

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

Special-Needs Collection

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

EQUIPMENT DEALERS

American
Discount Medical
Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @ www.AmericanDiscountMed.com
Our E-Mail address is: adm@information4u.com

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider.
Resource information: www.medmarket.com
e-mail: info@archhp.com

Ask about our Youth Brief sample pack. Only $5.99!

HDIS

FREE CATALOG

Call Today!
1-800-2MY-HOME™
(1-800-269-4663)

UNIQUE GIFTS

It's always the right time to appreciate those educators and healthcare professionals who work with our kids!
At **www.4medspeak.com** you will find unique gifts for speech pathologists, special ed teachers, therapists, home caregivers, pediatricians, etc.

MEDICALLY SPEAKING
www.4medspeak.com

FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg, PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

MONITORING SYSTEM

Care Electronics Inc.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price.
Call for FREE CATALOG

RESOURCES

EXCEPTIONAL PARENT

Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores all across America, every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books.
$4.95 Cover Price.

SWINGS

Portable Swing Stand

Therapy Swings

Safe, strong comforting & affordable for all your swinging and spinning needs

For more information contact
Take-A-Swing LLC
602-451-5544 • www.takeaswing.com

VAN CONVERSION DEALERS

MASSACHUSETTS

Motion Automotive Specialty
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—Day, Week or Month.

Announcing A Special Offer From EP Press

Patient Persistence

Adele M. Gill

ON SALE NOW!

This book celebrates the ability of people to overcome obstacles to achieve their goals. The author, Adele Gill, is a certified disability analyst, a Fellow of the American Board of Disability Analysts, and an advocate of inspirational and motivational self-help. Ms. Gill has divided the book into two sections, Hope and Courage. Both contain selections that deal with turning points in people's lives, times when they found strength, hope, and the courage to persevere in the face of adversity. This book offers help and hope to those who feel that their lives are out of control or that things have gotten so bad that there will never be a way to make them better. Through examples from the lives of real people, this volume demonstrates that there is always a way.

Code # EP8004GN Price ~~$19.95~~ **Sale $15.95**

No Apologies for Ritalin

Vidya Bhushan Gupta, MD

ORDER NOW & SAVE!

This book takes an in-depth look at attention deficit disorder/attention deficit hyperactivity disorder (ADD/ ADHD). Vidya Bhushan Gupta, MD, MPH, a Board-certified pediatrician and a Fellow of the American Academy of Pediatrics, is Director of Developmental-Behavior Pediatrics at Metropolitan Hospital Center, New York City. In his book, Dr. Gupta eloquently educates parents of children with ADD/ADHD about the disorder and available treatments, so that they can make informed choices for the care of their children. The first portion of the book describes what is medically known about ADD/ADHD, including causes and diagnostic methods; the second part outlines available treatment options, including Ritalin and other drugs, dietary changes, herbal therapy, and behavior modification. Dr. Gupta's purpose is to help parents of children with ADD/ADHD to stop blaming themselves for their child's disorder and to investigate and use appropriate therapies, including Ritalin and other medications when indicated, without guilt.

Code # EP8012AD Price ~~$19.95~~ **Sale $16.95**

These books are published by EP Press, the book publishing division of Exceptional Parent magazine, the country's oldest and most widely read publication for families of children and adults with disabilities and special health care needs and the physicians, allied health care professionals and special education teachers involved in their care and development. **For a limited time these books can be ordered at this special price by calling EP Library at 800-535-1910, or through their web site at www.eplibrary.com. Use coupon code: EP06015P**

circle #200

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

Send us your child's photo!

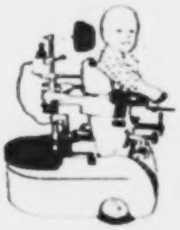
EP is always looking for submissions for our monthly *Familiar Faces* column.

It may just end up on our cover!

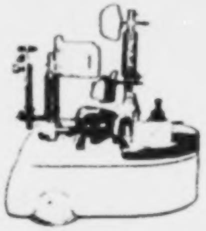
Send to: EP, 65 East Route 4, River Edge, NJ 07661

Early Childhood Mobility

Mini Go-Bot's

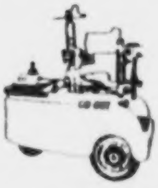


Century Stander

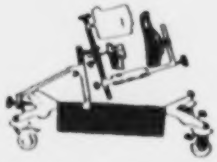


Stanford Standard

***Note:* Standing frames work with either Go-Bot**



Yellow Go-Bot



GB-I Gait Trainer
(can be customized)

Innovative Products, Inc.

1-800-950-5185

Web Site: www.iphope.com

Circle #46 or visit www.eparent.com/adinfo

Danny

by Rich Psillos

Danny doesn't cry. After all of the hardships he has been dealt, he doesn't complain. He doesn't sit there and ask why. He goes on with a smile like it is the best day ever.

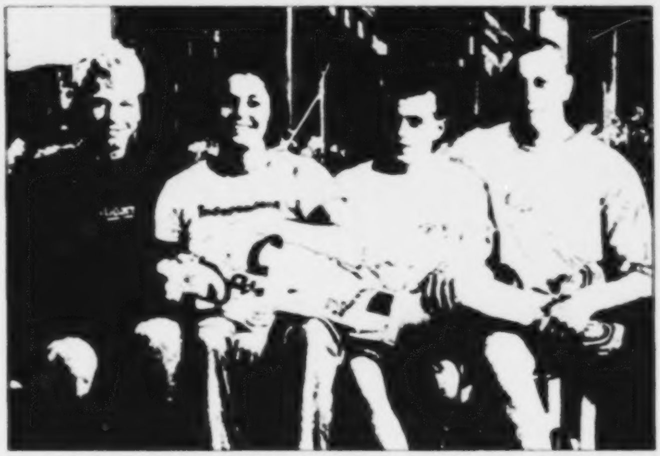
He is my little brother. He doesn't say more than a few words and can't understand much but he is the best thing that ever happened to me. He has helped me to realize how important life is and not to ruin it. Could you imagine not being able to tie your shoes or walk into the kitchen and grab something to eat? I couldn't. But since he has never had these luxuries, he doesn't realize what he is missing.

Every day when he wakes up, he is so excited to see my family. I wonder why? How could he be happy with all of his problems? When I wake up, all I say is, "Oh man, another day of school," not realizing that it is a blessing to be able to receive an education. I feel badly; I take my body and mind for granted sometimes.

I've also learned to be very affectionate, always caring and watching out for him. He's my brother and friend. I'm thankful he entered my life, changing me in so many ways. EP

My Brother

by Jessica Psillos



The Summer of 2001 brought everyone together for a picture. From Left to Right are Rich (17), Jessica (19), Charlie (13) and Joshua (16) Pictured Lying down is Daniel (8)

Everything will pass. Sometimes things happen and you think that they will last forever. But time passes and things change.

One of the biggest parts of my life is my youngest brother. He's severely handicapped. He's seven now and doesn't speak or walk on his own. I never knew that having a handicapped sibling would change my whole life, but it has. Every day is different because of him–our lives have a different way. Now that I have experienced life with him, I wouldn't want to change our situation. At times it is difficult, very difficult, but it's worth it.

MOM'S TURN

Kathy Psillos, mother of Rich and Jessica, writes:

Richie and Jessica wrote these articles while in their senior year of high school. I thought that parents of special needs kids might enjoy hearing about the positive effects of disabilities. I know it would have helped me in the beginning of our journey. Daniel has been a blessing in our home.

BEST COPY AVAILABLE

Submit your Children's Page to: EP, Attn: Children's Page, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number and e-mail address! ***Now on the Web!*** We now include **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

I want to make sure he's cared for all his life.

I'm Sarah, 43.

My son Jeremy has overcome many obstacles. Financial insecurity shouldn't be one of them.

MetDESK

My husband Bob and I want to make sure Jeremy is provided for when we're not around any more. So we talked to MetLife. Their MetDESK (Division of Estate Planning for Special Kids) specialists helped us with the many financial and legal issues in providing quality lifetime care for Jeremy. Since many of the MetDESK specialists are parents of children with special needs, they're knowledgeable and understand families like mine.

For more information on MetDESK call 1-877-MetDESK (1-877-638-3375).
Ask for our brochure *Planning for Your Child with Special Needs* or visit our web site at www.metlife.com/desk.

MetLife®
Financial Services

BEST COPY AVAILABLE

GET MET. IT PAYS.®

PEANUTS© United Feature Syndicate, Inc.

Metropolitan Life Insurance Company L00124ROY(exp1205)MLIC-LD

Circle #54 or visit www.eparent.com/adinfo

A Better Bedtime Story

The Vail Enclosed Bed

Once upon a time, parents of special-needs children dreamed of a way to make bedtim easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peac of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for you child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complet with mattress, manually adjustable hospital bed and vinyl border and bedskirt. Plus, we provide assistance in obtaining insurance approval.

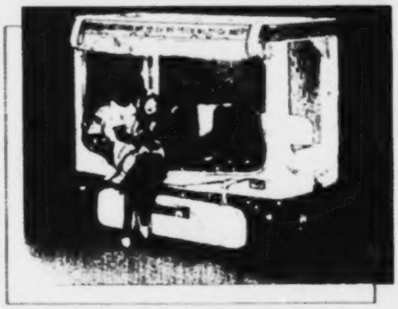
Available from home health-care products dealers, or direct from th manufacturer.

For a FREE catalog, call: 1-800-235-VAIL

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard



Ask about Our Decorator Accessories.

“Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep.”

Sheri Wittmer
Sandusky, Ohio

Vail Meadows Therapeutic Riding Center

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for challenged riders.

Circle #70 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent

AUGUST 2002
$4.95

BOSTON
RED SOX

Infant Healthcare

Special Report: EMPOWERING PARENTS

The Boston Red Sox, A Caring Team

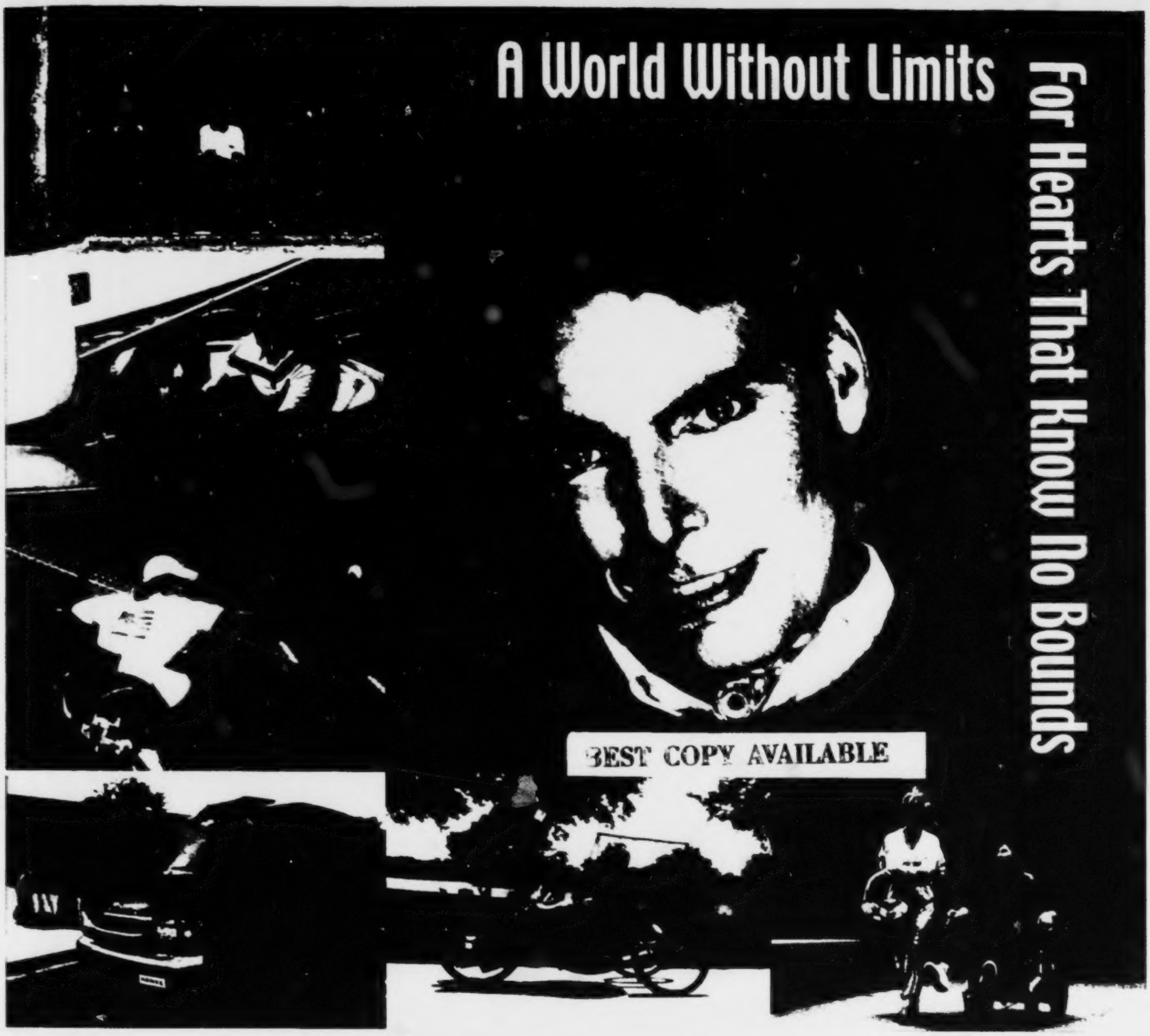
BEST COPY AVAILABLE

Learning Express
Your Neighborhood Toy Store
The Center for DISCOVERY
[illegible]
Cyberonics
UCP
ALLERGAN

*********************************FIRM 22201
22201GEE111NL00   ZNI02
JEPTHA GREER
COUNCIL FOR EXCEPTIONAL CHILDR
1110 N GLEBE RD STE 300
ARLINGTON VA 22201-4795
R= 7635
S109 P3

www.eparent.com

367


A World Without Limits
For Hearts That Know No Bounds

BEST COPY AVAILABLE

It's Ford Mobility Motoring's 10th Anniversary and Ford Motor Company's better idea of providing a comprehensive program of adaptive equipment information and credit assistance for Ford customers with disabilities and their families.

- Ford, Mercury and Lincoln cars, vans and light trucks. **Vehicle solutions** for every adaptive equipment need!
- Ford Credit Financing provides **purchase and lease solutions** accommodating the special vehicle needs of persons with disabilities and their families.
- Up to **$1,000 in cash** assistance for adding adaptive equipment to eligible Ford vehicles.[1]
- Adaptive equipment assessment centers and installer **resource listings** tailored to every state.

Begin your Ford Mobility Motoring experience by calling Program Headquarters.

1-800-952-2248 or
TTY 1-800-833-0312

Visit us on the World Wide Web
www.mobilitymotoringprogram.com

Ford Motor Company
MOBILITY MOTORING
Ford Credit
MOBILITY FINANCING

CHRISTOPHER REEVE PARALYSIS FOUNDATION

The Christopher Reeve Paralysis Foundation (CRPF) encourages and supports research to develop effective treatments and a cure for paralysis caused by spinal cord injury and other central nervous system disorders. The foundation evaluates and selects these research programs using councils of internationally renowned neuroscientists and clinicians. The Foundation also allocates a portion of its resources to grants that improve the quality of life for people with disabilities.

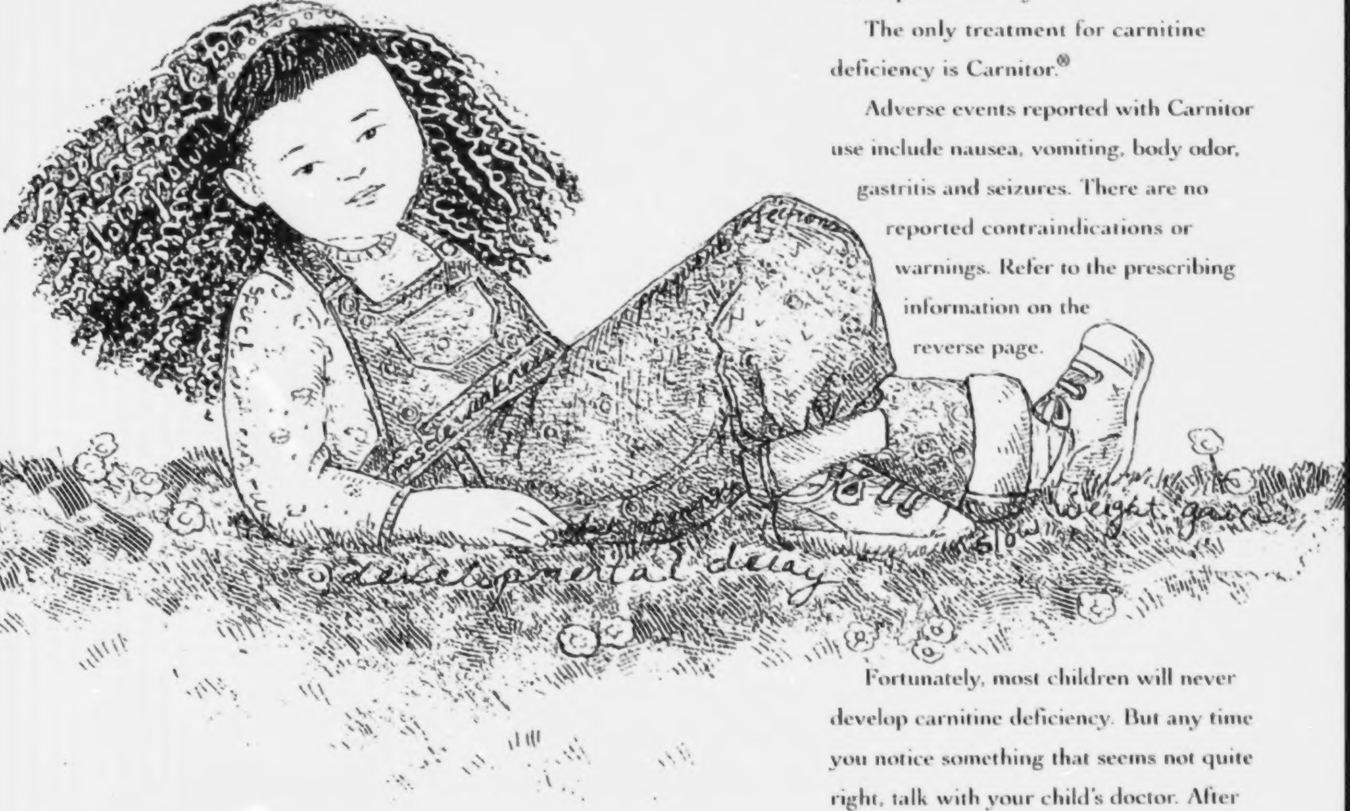
---

[1] The 2002 Ford Mobility Motoring Program is in effect from September 1, 2001 through August 31, 2002. The Ford Mobility Motoring Program will reimburse for the exact amount of the adaptation, up to $1,000 on adaptive equipment and up to a maximum amount of $200 for alert hearing devices, lumbar support and running boards, when you take retail delivery of a new 2001, 2002 or 2003 Ford, Mercury or Lincoln vehicle by August 31, 2002. Total reimbursement is not to exceed $1,000.

Circle #34 or visit www.eparent.com/adinfo

MA7085/04-02

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?



No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.

Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor® levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Circle #55 or visit www.eparent.com/adinfo

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occuring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that binaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 μmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

contents

AUGUST 2002 ◦ VOLUME 32, ISSUE 8

INFANT HEALTH

& DEVELOPMENT

24 Healthy Start: Good Nutrition for Babies with Special Needs
By Christine Wood, MD.
Tips on how to keep your baby's diet healthy through nutrition and feeding techniques.

26 The Just Right Challenge
By Megan Henninger
A look at pediatric PT displays that the challenge of Physical Therapy must be "just right" for both parents and children.

30 Infant Development Specialists: Playing with Babies, Helping Them Grow
By Linda S. Dingman, MA
A personal tale of an Infant Development Specialist's daily tasks and responsibilities.

34 Universal Newborn Screening: An Update
By Julia Steele
A new look at Newborn Screening including an updated chart of which states test for which disorders.

SPECIAL REPORT:

96 Informing, Empowering and Keeping Parents Involved: A Four Part Series
by Cynthia Whitfield
Part III: Transition & The Planning Process—It's All About Choices

96

20

FEATURES

20 Fenway park, Historic Venue for August Disabilities Night
How EP works to expand awareness through Disability Awareness Nights at both Fenway Park and Yankee Stadium, and the story of Timmy and Ellen Stevens who work to give back.

42 We are Stardust, We are Golden
By Marianne Taylor
Reflections on an International Conference on Practice and Professionalism

42 Respite: A Consumer's Perspective
By Dani & Gene Feierstein
Ideas for how parents and caregivers can find time away from their children.

46 Lifting and Carrying Children with Special Needs: Back Injury Prevention for Parents
By Carolyn Cantu, MS, OTR
An occupational therapist's guide to back safety for parents and other professionals caring for people with disabilities.

58

58 Adapted Sports and Recreation
How technology and equipment help to improve participation in sporting events and other recreational programs

66 The Jungle of Unoland: A Fable for Our Time
By Vidya Bushan Gupta, MD
An explanation of the war on terrorism for young children.

68 Serena's Song
By Carolyn Cantu
A personal account from aboard the first wheelchair-accessible hot air balloon

68

70 A Physicians Question
By Galina Psakhis, MD
A medical resident wonders why healthcare professionals are not given more training in how to best serve patients with disabilities.

76 Ignorance is Unmasked and Stereotypes are Explored in This Summer's Unconventional Romance, *Pumpkin*
By Jennifer Kirby
Christina Ricci discusses her new movie as well as her feelings on the treatment of those with disabilities.

85 Record Keeping for the Medically Complex Child: Having the Answers Ready
By Barbara Robbins
One parent's plan to help keep extensive medical records readily accessible when they're needed.

ON OUR COVER: Ellen and Timmy Stevens.

EP
Exceptional Parent

contents

DEPARTMENTS

8 **Editor's Desk**

10 **Search and Respond**

52 **Organizational Spotlight**
The Muscular Dystrophy Association

73 **Tech Talk**
By Sheryl Burgstahler
Strategies and other thoughts about getting involved with this new way to make a friend.

78 **EP Library**

80 **What's Happening**
- E-Buddies • Ziggy • Report to Congress
- Anne Ford Scholarship • Hugs and Hope
- Osgood–Schlatter on the Rise • Special Toys for Special Kids

83 **Further Reading**
By Megan Henninger
- Getting Involved in Choosing Staff: A Resource Pack for Supporters Trainers and Staff Working with People who Have Developmental Disabilities.
- The Physicians Guide to Caring for Children with Disabilities and Chronic Conditions
- Caregivers and Personal Assistants: How to Find, Hire and Manage the People Who Help You (Or Your Loved One!)

84 **Familiar Faces**

88 **Research Reflections**
By Dr. Jan Blacher
This Time From Abroad
An inside look at the research presented during the International Association of the Scientific Study of Disability held in Dublin, Ireland.

104 **New Products**

108 **Children's Page**
By Alycia and Gina Crilly
Our Little Angel

EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTH-CARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy-Ed Corp., dba *Exceptional Parent Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy-Ed Corp. *Exceptional Parent*® is a registered trademark of the Psy-Ed Corp. **Postmaster:** Please send address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *Exceptional Parent*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #4006 0754. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

Exceptional Parent neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
While hyperbaric oxygen is effective therapy in certain conditions it is currently considered an alternative therapy for CP and other "brain insult" conditions. Readers are advised to discuss the advisability of HBOT with their primary or specialty healthcare providers as well as to study the current literature.
—Rick Rader, MD

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

MITCHELL F. BRIN, MD, Vice President, Botox, Allergan, Irvine, CA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics , Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof. Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

HARILYN ROUSSO, ACSW, Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

HAROLD TURNER, D.D.S., Editor Emeritus, Oral Health

THERESA VARNET, MSW, JD, Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

Informed Parents

Where Parents Keep Up To Date On Products For Their Children's Special Needs

New Products

NEW CATALOG
ORDER YOURS NOW

- **Standing**
- **Gait Training**
- **Shower/Bath**
- **Seating Systems**
- **Transportation Safety**

New Information

Call Today For Your

FREE CATALOG

1-800-336-7684

Therapist Tips

Education Series

SNUG SEAT®

Circle #56 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

Publisher's Letter

Parenthood is for many of us the most rewarding, yet most challenging aspect of our lives. For parents of a "special child," this is particularly true.

Parenting a special needs child requires special commitments. Sometimes, these commitments become overwhelming, even daunting. That is why The Center for Discovery has underwritten an unrestricted grant to EP for the purpose of exploring the very real emotional issues and difficult decisions parents/families have to address in order to meet the lifelong needs of their child.

EP has been proud to research and publish this four-part series whose mission, coincidentally is four-fold: to educate parents about what resources are available to them; to expand awareness as well as horizons about alternatives; to empower parents to make informed decisions without guilt or regret and to engender action. We call these the Four Essential Elements of Family Centered Care. The third segment of this four part educational series appears in this month's issue and all four parts are available on our website www.eparent.com. Through the chronicling of real-life families and helping them evaluate the emotional, financial and overall considerations that affect everyone involved, The Center for Discovery and EP hope to help parents make informed choices on behalf of their children.

As we all know, the special education service delivery system comes in many sizes from full inclusion to residential placement. Providing guidance to recognize the nature of the "right size" services to meet each individual child's needs is what this educational series is all about. Equally as important, the series provides needed practical advice and emotional support with respect to how parents and caregivers can obtain those targeted services.

The series also tries to help parents discern the quality of programs. We must always remember that it is the responsibility of any good education program to change and adapt to the needs of the individual so as to effectively move the child forward. It is not the child's responsibility to "fit" into what is being offered.

As you read the articles included in this series, you may have thoughts or suggestions. We welcome them and hope you write or email us at http://www.edit.eparent.com. These articles are part of an ongoing effort by EP in the special needs area to insure the efficient use of all available resources for the purpose of helping the single greatest treasure we have as a nation and as a people... our children!

Sincerely,

Joseph M Valenzano

Joseph M. Valenzano, Jr.
President CEO & Publisher

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

EDITOR-IN-CHIEF Rick Rader, MD
CONSULTING MANAGING EDITOR Donald P. Mazzella
MEDICAL EDITOR Fern R. Potvin
SENIOR EDITOR Megan Henninger
ASSOCIATE EDITOR Laura Apel
ASSISTANT EDITOR Julia Steele
ASSISTANT EDITOR Maria Tortoreto
INFORMATION SYSTEMS COORDINATOR Dennis Dusevic
RESEARCH ASSISTANT Susan Jenkins
GRAPHIC CONSULTANT Dennis Wilkes

PRESIDENT, CEO & PUBLISHER Joseph M. Valenzano, Jr
VP BUSINESS DEVELOPMENT & INTERNET PROJECTS Vanessa B. Ira
CHIEF FINANCIAL OFFICER Dolores A. Kinley
AD TRAFFIC MANAGER Kendra Kelly
SALES COORDINATOR Doris DeFina
RECEPTIONIST/PUBLIC RELATIONS COORDINATOR Robyn Sager
ART DIRECTION, DESIGN Publishers Design Group, Inc.
✉lannpdg@aol.com
PRODUCTION MANAGER Michael Longobardi
EP LIBRARY Ron Richards
(800) 535-1910
✉eplibrary@aol.com
WEBMASTER Ken Fleischer, Dynamic Media Works
✉webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Vanessa B. Ira
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 ext. 209
✉ vira@eparent.com
CANADA

Annabelle & Gabe Jacobson
(847) 256-6850
✉ bellyon@megsinet.net
MI, WI, IA, IL, IN

Bill Joubert
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ bjoubert@superlink.net
MT, ND, MN, SD, WY, NE, KS, OK, TX

Jared Adams
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉jadams@eparent.com
DE, MD, DC, WV, VA, NC, SC, GA, FL, KY, TN, AL, MS, LA, AR, MO

Matt Valenzano
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 x211
✉mattvalenzano@eparent.co
ME, VT, NH, MA, RI, CT, NY

Brian Regan
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
PHARMACEUTICALS

Larry Battistello
Marketing Plus
3155 East Ramon, Unit #203
Palm Springs, CA 92264
✉ seeme4ads@aol.com
TERRITORY: WA, OR, ID, NV, CA, UT, CO, AZ, NM

Barbara Nastro
65 East Route 4
River Edge, NJ 07661
(908) 534-6366
(908) 534-6941-fax
✉ nastro@blast.net
NJ, PA, SCHOOLS, CAMPS & RESIDENCES, MARKETPLACE

COLOR SEPARATION/FILM PREPARATION
AGT7 Carlstadt, NJ 07072

LIST RENTALS
GRS
Mktg Services Inc.
187 Billardvale Street
Willington, MA 01887
Attention: Mark Hammar
978-661-8126
mhammar@mktgservices.com

PUBLISHING & EDITORIAL OFFICE
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

SUBSCRIBER SERVICE:
EXCEPTIONAL PARENT
P.O. Box 2078, Marion, OH 43306-2178.

CUSTOMER SERVICE/NEW ORDERS:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

EXCEPTIONAL PARENT magazine was founded in 1971 by
Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 90

Photo courtesy of Midland Daily News.
EDEN ORGANIC APPLE JUICE
ORIGINAL EDENSOY ORGANIC SOYMILK EDEN
EDEN SELECTED OLIVE OIL Spanish Extra Virgin
EDEN ORGANIC Endless Tubes Rigatoni
EDEN ORGANIC Diced Tomatoes with Green Chilies
EDEN ORGANIC LENTILS
EDEN ORGANIC KIDNEY BEANS
EDEN ORGANIC BARLEY MALT
EDEN ORGANIC UDON PASTA

Ⓚ parve

Pure Food our Passion
Great Taste our Joy

Our food is sought out by people worldwide who desire the highest quality, safest, most nutritious, delicious, certified organically grown and produced kosher food. Eden offers over 150 Ⓚ parve, organic foods.

www.edenfoods.com

EDEN®

375

©2002 Eden Foods, Inc. • Clinton, Michigan 49236 • 1 888 424-EDEN

Circle #31 or visit www.eparent.com/adinfo

Save 50¢
On any
EDEN Product

EDEN.

EDENSOY EXTRA
EDEN GARBANZO BEANS
EDEN ORGANIC Pizza Pasta Sauce
EDEN ORGANIC Vegetable Spirals

MANUFACTURER'S COUPON | EXPIRES 11 / 30 / 02

Consumer: Coupon good only in USA on purchase of brands / size indicated. Void if copied, transferred, prohibited or regulated. **Retailer:** Eden Foods, Inc. will reimburse you for the face value of this coupon plus 8¢ handling if redeemed in compliance with our redemption policy. Copy sent upon request. Invoices proving purchase of sufficient stock to cover coupons must be shown on request. Face value .001¢. Mail coupon to: **CMS Dept. #24182; One Fawcett Drive; Del Rio, Texas 78840**

Expires: November 30, 2002 **10695**

5 24182 00050 9 (8101)0 10695 1102

editor's desk

The Heart of a Lion, The Eye of an Eagle and The Wisdom to Gift Them

ILLUSTRATION BY MS. MEMORY COLLINS

I love my organs. Sure, with some of them it's more like a love-hate relationship, but I greet them enthusiastically every morning.

Readers of EP know all too much about organs. In fact sometimes I think a better title for this monthly would be EO, Exceptional Organs. Because organs, the way they don't always develop, function, and play nicely with each other, are the soul of this magazine. Readers of EP magazine live and breathe for and because of organs that march to the sound of a different drummer.

In fact, every day, sixteen people die waiting for an organ transplant. There are more than 80,000 people on waiting lists for life-saving critical organs. Hundreds of thousands more would benefit from a life-enhancing tissue replacement, such as skin or cornea transplants. Every year these numbers increase. Every year the number of people willing to donate organs when they die decreases.

I'm not writing to continue clearing the way for persons with disabilities to receive organ and tissue transplants; that frontier has pretty much been fortified. I'm writing to introduce the notion that individuals with developmental disabilities and their families have the right, obligation and wisdom to participate in the national call for people to consider being organ donors.

First, it is a legal right of all citizens to donate their organs and tissues. The Uniform Anatomical Gift Act specifically recognizes this right. All organ donors are evaluated on an individual basis. There is no inherent reason why citizens with developmental disabilities would be unsuitable candidates for organ donation. The only exceptions are those candidates who have extracerebral malignancies or unresolved transmissible infections, such as AIDS or hepatitis B.

When Dr. Chris Prater, my colleague at Orange Grove, and I made inquiries about the possible genetic contraindications to people with developmental disabilities making organ donations (and we communicated with genetics researchers, organ procurement specialists, transplant surgeons and immunologists), no one knew of any. This demonstrates another aspect of the non-personhood status of our population.

There are many reasons why physicians have not been more effective in the arena of organ procurement. Focus groups of doctors have concluded that the barriers to physician involvement include:

- lack of time to discuss organ donation with family;
- tensions between physicians and organ procurement organization staff;
- fear of perceived or actual conflicts of interest;
- unwillingness to address the issue in nonurgent settings;
- inadequate knowledge of regulations and protocols;
- discomfort with the subject; and
- lack of training in recognizing medical futility.

Add the above to the physician's lack of comfort and appreciation for the Exceptional Parent, and the chances of having a physician approach the family of a child with special needs about organ donation are slim.

So once again it's up to you, the parents. You've changed doorway dimensions, laws, funding exemptions and attitudes, and you can change this. I'm proud to say that my colleagues, in concert with the parents at Orange Grove, are starting to explore the various ways in which this issue can be addressed.

It is the purpose of this editorial to advocate and endorse the consideration of organ and tissue donation as part of the life plan of a person with developmental disabilities. It's not about giving back; it's not about perpetuating souls, spirits or legacies. It's about announcing to the world that people with disabilities have something to give, because all along they've had something to share. All along they've shared needs, hopes, dreams—and organs. EP

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

For further information contact:

- American Medical Association's web site on organ donation:
  http://www.ama-assn.org/go/organdonation
- US Dept. of Health and Human Services' Organ Donation Initiative
  http://organdonor.gov/
- United Network for Organ Sharing (UNOS):
  1-800-24-DONOR or http://www.unos.org
- Brain and Tissue Bank for Developmental Disorders
  Children's Hospital of Orange County/ Dept. of Neurology/
  455 South Main Street/ Orange, CA 92868-3874 Tel. 714-516-4310
  http://www.nhnscr.org/donate/donate.htm
- The Living Bank Uniform Anatomical Gift Act Donor Form
  Available from: The Living Bank
  P.O. Box 6725/ Houston, TX 77265 Tel. 1-800-528-2971
  http://www.actec.org/pubInfoArk/livingbank.html

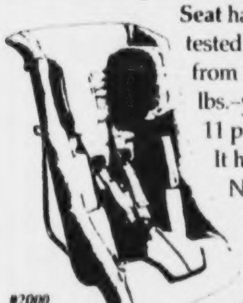
Johnny, 51 lbs. and 48" tall, in the Columbia Car Seat

Sharing the Caring

Columbia offers you solutions to the daily challenges of transporting, bathing and toileting your child – *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

☐ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.–yet weighs only 11 pounds! It has been the No. 1 choice since 1986, for its adjustability and stylish comfort.


#2000 Car Seat

■ At bathtime, our popular **Reclining Chairs** and **Wrap-Around Bath Supports** allow your child – and you – to enjoy the bath.

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

#7700 Hi-Back Wrap-Around Support

■ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.

Why do these products work so well? Columbia products are thoughtfully designed, with each item available in the **right size for your child,** with lots of adjustability for a custom fit. They are made of durable materials, tested and proven in real-life experience. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

#4200 Small Support for children

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

COLUMBIA
SHARING THE CARING

Circle #25 or visit www.eparent.com/adinfo

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG
Columbia Medical Mfg. Corp., Dept D1, P.O. Box 633, Pacific Palisades, CA 90272
Visit Our Web Site at http://www.ColumbiaMedical.com

377

Search & Respond

S

Sleep Problems

My 17-yr-old son has Klinefelter syndrome, VATER syndrome, Horner's syndrome, and brain damage from a lack of oxygen at birth. He developed a seizure disorder two years ago and after many allergic reactions to standard drug therapies was placed on Keppra and Ativan. He has also developed a sleep disorder, always staying awake for more than 24 hours, and often only falling asleep after experiencing a seizure. He can become quite combative, hitting himself and others. He is also on Zantac (post anastomosis for esophageal atresia) for GERD and Valium for sleep (which does not get him to sleep but helps a bit with the combativeness). Has anyone else had these problems with these medications?

– JS, 935, via EP Web Site

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to eped-it@aol.com; or visit Search & Respond on our web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

EDITOR: Although not a panacea, melatonin (a natural hormone in the body that induces sleep) can be taken orally and sometimes helps people with brain injury or other cognitive or emotional disabilities to sleep better.

S

Combative Sleeping

I am the foster mother to a young man with Down syndrome. He has also been diagnosed with Tourette syndrome. He has a particular behavior that I am very concerned about. When he is asleep at night he will begin to pound his head with his fist over and over, never varying from the same spot on his head. When I tap him to turn over (I can hear it all the way from my room), he immediately repositions himself and the hitting stops. It will then continue off and on during the night. He has had an EEG (for seizures) which showed negative results. If you've ever heard of this or have any suggestions, I would really like to hear from you.

– SB, 937, via EP Web Site

S

Vomiting as a Self-Stimulation Behavior

I am a consulting teacher for special education programs. Two students, in different schools, are vomiting at both school and home, apparently as self-stimulation. One student puts his finger down his throat and vomits, while the other usually gags and then spits up. This week, however, he gagged until he vomited. In both cases, the doctor has ruled out biological causes of the behavior. Any help with how to stop this particular type of self-stimulation would be greatly appreciated.

– CB, via EP Web Site

S

Looking for Support

I am desperately looking for a link to a web site or a chat room for parents of children with disabilities or special needs. I just need a place that I can go from time to time to speak with others who are in a similar situation. Sometimes the stress makes me feel I am alone, which I know is not true. My son Cody is 7 and he was born with severe hydrocephalus, and brain damage that has left him with CP. He uses no speech (just screaming), experiences seizures, has low muscle tone, vision problems and is wheelchair-dependent. Just looking for others that are going through the same challenges to chat with from time to time. Thanks!

– SR, via EP Web Site

S

Down Syndrome Menstruation

I have an 8-year-old daughter with Down syndrome. I am searching for anyone who can give me information on what to expect when my daughter begins menstruation. I have heard very little other than that medication is given to stop the cycles in some cases (but I don't think it was related to DS). She will be 9 in December and I know this may be a bit early, but I feel I need to start exploring options now. If anyone can

continued on page 12

I want to make sure he's cared for all his life.

I'm Sarah, 43.
My son Jeremy has overcome many obstacles.
Financial insecurity shouldn't be one of them.

MetDESK

My husband Bob and I want to make sure Jeremy is provided for when we're not around any more. So we talked to MetLife. Their MetDESK (Division of Estate Planning for Special Kids) specialists helped us with the many financial and legal issues in providing quality lifetime care for Jeremy. Since many of the MetDESK specialists are parents of children with special needs, they're knowledgeable and understand families like mine.

For more information on MetDESK call 1-877-MetDESK (1-877-638-3375). Ask for our brochure *Planning for Your Child with Special Needs* or visit our web site at www.metlife.com/desk.

MetLife
Financial Services

GET MET. IT PAYS.

BEST COPY AVAILABLE

PEANUTS© United Feature Syndicate, Inc.   Metropolitan Life Insurance Company   L00124ROY(exp1205)MLIC-LD
Circle #47 or visit www.eparent.com/adinfo

continued from page 10

please help or share their experience with me it would be of great help.

– DD, 958, via EP Web Site

EDITOR: The onset of menstruation for young women with Down syndrome, although a challenge, is not necessarily a problem that requires medical management. Lots of teaching and loving support may be all that's needed. Sometimes, however, personal hygiene care proves to be just too difficult. In such cases, the menstrual cycle, which typically occurs monthly, can be modified to occur only once every 3 or 4 months by using one of the oral contraceptive pill formulations, in a modified dose, with the guidance of a doctor.

Chewing Clothing

My son had brain damage when he was born due to an intrauterine infection. One of the effects is that he chews whatever fabric he can get his hands on. The only way we have been able to deal with this is to keep chewable fabric out of his reach. He wears a windbreaker jacket most of the time. The material, being tougher, is therefore more difficult to chew through. He does eventually chew through it, but it's a lot less expensive to replace one jacket every few months than a shirt a day. Also, he uses an unzipped sleeping bag for a comforter because it is made from thicker fabric. We tried putting him on Zoloft, an anti-depressant also used for obsessive compulsive behaviors. His chewing did not change and now he refuses to eat anything that isn't mush! Please let me know if anyone has suggestions to improve this situation.

– MG, via EP Web Site

Respond

VNS Concern

KD has a 7-yr. old daughter who is developmentally delayed, has a seizure disorder, and doesn't talk. The doctors have given the ok for her to have the Vagus Nerve Stimulator Procedure, and she is curious about other experiences with VNS.

My daughter had VNS installed in September 1998 and has responded very well. We were able to decrease from four medications to one for almost a year. I would recommend VNS when other brain surgery or use of a ketogenic diet is not an option, as with my daughter. So glad we did the VNS.

– JT, 1296, via EP Web Site

Alternative AFOs

My son wears AFO's and we have found that Teva sandals work if you extend the straps. This is easily done using velcro strips (found in any fabric shop). 1) Take a strip of the "soft" part (where the velcro teeth attach to) and place it over the "hard" part of the Teva strap, leaving a few inches to extend beyond the strap. 2) Place the "hard" part over the soft part, again leaving a few inches to extend beyond the soft part. 3) Attach the "hard" part of the velcro to the Teva sandal. Hope this helps.

Solutions for Wet Nights

Bed Bath and Beyond sells a plastic "bag" to protect mattresses. It works very well. You may want to try it on the comforter too. Also, we put an extra diaper on our son at night that goes horizontally over his stomach, which we tape to his regular diaper. It provides an extra couple of inches of absorption above the regular diaper and it makes a big difference.

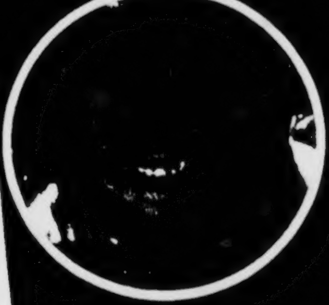
– MG, via EP Web Site

College for Those with LD

V has a 16-year-old son with a learning disability who is looking for information on appropriate colleges to attend.

There are many colleges that are just starting to include accommodations for student's with LD and ADHD. It is important to check out the program, talk to other LD students who also attend that college, and get statistics of graduates with LD. My stepdaughter is currently 24 years old and has both LD and ADHD. She attended Rainy River Community College for two years and did not earn her AA degree there because she did not pass some courses. Augsburg College in Minneapolis, MN accepted her, and she began her work there. She earned her AA degree by transferring classes. She graduated with her BA this May after six years at Augsburg. She has attended classes every summer to retake classes she has had problems with in a lighter course load. At Augsburg, students have LD specialists and are able to get the help they need. I also have a nephew who has LD and ADHD. He is 18 years old and a senior in high school. He is choosing to attend Hennepin Technical College in Eden Prairie, MN. This technical college offers LD support and a specialist to help him as well. Do not shut out the idea that learning a trade may be an option your child may want to pursue. The one thing to remember is that your child is an adult. This is a time when parents must step back and let the student be their own advocate.

continued on page 14



Quality for life

The Bugsy walker's maximum adjustability and solid, lightweight construction provide safety, convenience, and functionality like no other.

The Bugsy's highly adjustable design encourages active postural control during standing and walking, while also promoting a more natural movement. Unlike other walkers, Bugsy's solid rubber wheels feature stainless steel ball bearings for smooth, easy maneuverability. The anti-reverse wheel design prevents inadvertent backward rolling for safety. Lightweight construction and a quick fold-up feature provide easy handling and storing.

Contact your Otto Bock Sales Representative (U.S. 1-800-328-4058 or Canada 1-800-665-3327) to see the Bugsy pediatric postural walker firsthand.

Otto Bock
HEALTH CARE

www.ottobockus.com
www.ottobockcanada.com

CONTROL

Handlebars are height and depth adjustable to accommodate growth and gait patterns.

Optional positioning aids, such as upright handlebar with forearm pads provide stability and postural support for children unable to use the standard handlebar.

Lightweight and easily folded for added convenience.

Optional swivel wheel locks and rear friction brakes provide directional control and extra safety.

Soft, solid rubber wheels with stainless steel ball bearings provide easy rolling and maneuverability even under heavy pressure.

Optional hip pads and seat

Optional back support and handle grips with wooden stops

Circle #50 or visit www.eparent.com/adinfo

© 2002 Otto Bock Health Care U.S., Inc. Cloud is a trademark of Otto Bock Health Care U.S., Inc. 20020405.4

381

continued from page 12

LD students have learned to accept defeat and try again–a valuable lesson for college life. You may also find the book *Succeeding with LD: 20 true stories about real people with LD* by Jill Lauren, MA helpful. This book describes a lot of people with LD who have been successful in college.

– CP, via EP Web Site

I am coordinator of a clinic for those with cerebral palsy and other neuromuscular disorders. We have two patients that are currently enrolled in the PACE Program at National-Louis University in Evanston, IL. They are from Michigan and can live away from home. They and their families absolutely love it. There is financial assistance available. Also, check out the *Peterson Guide to Colleges with Programs for Learning Disabled Students*, by Charles Mangrum, II, Ed.

– AD, 1315, via EP Web Site

Instant S&R

School Yard Harassment

My 14-year-old son has mild to moderate mental retardation, a speech difficulty and learning disabilities. He has been in special ed classes since he was three years old, and now attends a middle school where his special ed class is a separate entity from the main school. His previous educational experiences were in environments where non-disabled children became "buddies" with the special ed kids, i.e., had reading time together, were partners at assembly, etc. Now, in middle school, there is no such interaction and my son is being cruelly taunted, called "loser," etc. and will walk all the way around a building to avoid contact with his tormentors. I know these kids just don't know any better, or are afraid of the differences between themselves and special ed kids. I was hoping someone out there could give me some help on what to do for my son to heal his very sensitive feelings and give him some encouraging/coping skills, as I know this will not be the last situation in which he faces people who don't understand. I also wanted to know of any way I can get the school to integrate rather than ostracize, to help these kids understand and have some empathy and compassion for each other. Thanks for any and all help.

– 598, via EP Web Site

Have you ever informed the school of what's going on? Your son has the right to be safe in school, both physically safe and emotionally safe. Check with your state's attorney general and see if there are any hate laws on the books. Also, the US Deptartment of Education sent a letter to all state departments of education on the need to protect kids in special ed from abusive situations. This includes verbal abuse. Also, find out what the school's policy is on racial slurs. If they have a zero tolerance for harassment on the basis of race and gender, but "look the other way" when it comes to disability harassment, then they are violating the Americans with Disabilities Act (Title 2) and Section 504 of the 1973 Rehabilitation Act. Schools MUST comply with both laws (even though many will try to tell you they don't have to). Don't let this slide. Your child has the right to go to school without fear. Plus, by seeing your response, your son will learn that it is possible to stand up for your rights, a lesson he will need later. Good luck,

– CJ via EP Web Site

We have a person we call a Tracker. This person makes sure that the child gets from one place to another without being harmed (either mentally or physically). The trackers also help in the different classrooms, so children can be integrated with the "normal" students. The trackers make sure that the work is done to the ability of the students, and inform parents with daily notes to help the parent see what the child is accomplishing. With the right person and training this can be very helpful in putting our children in regular schools and preventing their seclusion from society. Everyone has the right to be treated as a regular person despite our differences!

– SN via EP Web Site

We're Expanding

Due to the high volume of letters we receive and the popularity of this department, **Search and Respond** will now be three pages long. Please continue to send us any questions and comments that you may have, either through the mail or online at http://www.eparent.com

no more
frustration -
just fun

LECKEY®

Advance Bath Chair

New Design

The most extensive height range and adjustable seat angles make bath positioning easy.

Extra-soft mesh material and padded support bars give your child a more comfortable and enjoyable bath time.

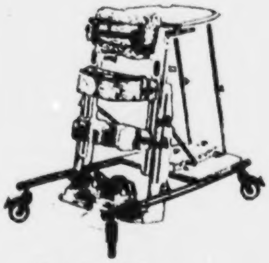
Take the Advance Bath Chair from the tub to the shower with the optional trolley

Also available is the Basic Bath Support that provides adjustable positioning angles at a fixed height.

And The FUN Doesn't Stop There

Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Call us today for more information.

- *Lighter mobile bases*
- *More adjustable components*
- *Peer level positioning*
- *Child friendly positioning straps*
- *Playful colors*



Pronestander

Freestander

Totstander

Toilet/Shower Chair

Easy Seat

SAMMONS® PRESTON
AbilityOne

Leckey® products are brought to you exclusively by Sammons Preston®

Start the fun today! Contact your local Sammons Preston distributor or home health dealer for more information.

Or call Sammons Preston at
1-800-323-5547

Circle #54 or visit www.eparent.com/adinfo

HARD MANUFACTURING

AGE APPROPRIATE BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

The Stockton features full crib safety sides

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #39 or visit www.eparent.com/adinfo

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C. & Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #45 or visit www.eparent.com/adinfo

Fenway Park, Historic Venue

The Boston Red Sox and Exceptional Parent Magazine will be hosting the first Disability Awareness Night at Fenway Park in Boston on August 20th, 2002.

In cooperation with the United Cerebral Palsy Foundation, Easter Seals and the Tourette Syndrome Foundation, Exceptional Parent Magazine and the Boston Red Sox want to call attention to Americans with disabilities.

In a pre-game ceremony at home plate, State Senator Fred Berry of Mass. will be honored for his outstanding

Timmy Stevens (pictured above with Red Sox shortstop Nomar Garciaparra) and his mom Ellen work to give back to both the Professional Center for Child Development (PCCD) and the Children's Hospital in Boston, MA. Timmy, who is ten years old, has cerebral palsy, seizure disorders, cortical vision impairment and osteopenia. He and Ellen have helped to raise money for Timmy's school and the hospital by participating in fundraisers and charity events.

This mother-and-son team first got involved eight years ago, through a road race for the PCCD called Trot for Special Tots. This event has become tradition for the Stevens family, with either Ellen or another family member pushing Timmy's chair in the race each year. For the past two years, Timmy has also been a "patient partner" with the Kids at Heart program. The program matches kids with runners in the Boston Marathon who race to raise money for

BEST COPY AVAILABLE

for August Disabilities Night

the Children's Hospital.

Last year, Timmy was one of three children to represent the hospital at the CIBC World Miracle Day, an annual event that benefits many different children's charities. Every year, many of the trading staff at CIBC donate the commissions they generate on "Miracle Day" to children's charities across the country and around the world.

Ellen says that being involved in these events has been a wonderful and exciting experience for her and her son. They have met many other families, as well as some interesting celebrities such as former Bruins player Cam Neely.

Timmy (left) and Ellen Stevens with cousins Tommy and Jimmy at the PCCD Trot for Tots.

While this kind of involvement has been great for the Stevens family, Ellen says that parents should not feel obligated to give back in this way. "Only if they have the time and energy," she says. "The most important thing is to keep your child healthy."

BEST COPY AVAILABLE

dedication to people with disabilities. He will be presented with the Maxwell J. Schleifer Distinguished Service Award. Maxwell J. Schleifer was one of three co-founders of Exceptional Parent magazine 31 years ago.

The event will be similar to the one held at Yankee Stadium on July 3, which honored US Marine Corps Commandant James L. Jones and his wife Diane, as well as Bill Porter, the star salesperson who overcame childhood disabilities.

The New York Yankees and the Boston Red Sox have been the first teams to "step up to the plate" for disability awareness. They have done numerous things in their respective communities to help people with disabilities.

Exceptional Parent is developing additional events to promote disability awareness. The Atlanta Falcons will be holding an awareness day this fall at Turner Field in Atlanta. EP

Disability Awareness Night

"DISABILITY AWARENESS NIGHT AT YANKEE STADIUM"
verizonwireless
VISA VISA
HESS
BORN ON DATE
AIG
BUD LIGHT

Above: US Marine Corps Commandant James L. Jones (extreme right) is honored by EP President, CEO and Publisher Joseph M. Valenzano, Jr. The Commandant's wife Diane was also honored. Their daughter, Jenny Jones, has Fragile X Syndrome.

Above: Bill Porter's story inspired the television movie *Door-to-Door* which chronicles his success as a salesperson. Shelly Brady is also depicted in the movie as his helpmate. New York City Police Commissioner Ray Kelly presents the award at home plate.

Left: Shelly Brady and Bill Porter accept applause at Yankee Stadium during Disability Awareness Night ceremonies.

BEST COPY AVAILABLE

888

Lou Rocco/New York Yankees

at Yankee Stadium

The Commandant tosses out the first ball as New York Yankees pitcher David Wells looks on.

Yankees catcher Jorge Posada presents a souvenir ball to Marine Corps Commandant James L. Jones at Disability Awareness Night at Yankee Stadium.

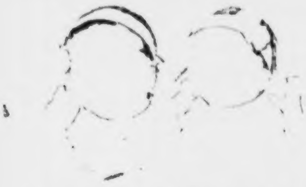
Disability Awareness Night at Yankee Stadium was made possible with the help of The Center for Discovery, Sigma-tau Pharmaceuticals, Inc., Cyberonics Inc., United Cerebral Palsy and the Child Neurology Society.

Below: Marine Corps Commandant James L. Jones accepts the special recognition award from EP Magazine's President and CEO Joseph M. Valenzano, Jr. Looking on are his daughter Jenny and his wife Diane, who was also honored at the event on July 3, 2002.

In ceremonies at home plate, Commandant James L. Jones is honored along with his wife Diane (to his left) and daughter Jenny, who has Fragile X Syndrome. Also honored was Bill Porter (center), whose life is celebrated in the television movie, *Door-to-Door*. To his right is Shelly Brady, who is a central figure in his life and movie. To Bill Porter's left is New York City Police Commissioner Ray Kelly and EP President, CEO and Publisher Joseph M. Valenzano, Jr. Paul Burke, Director of Marketing for United Cerebral Palsy is directly behind Mrs. Jones and Shelly Brady.

BEST COPY AVAILABLE

889



Healthy Start

Good Nutrition for Babies with Special Needs

By Christine Wood, MD,
author of "How to Get Kids to Eat Great and Love It!"

As a pediatrician, I know first hand how concerned parents can be about their child's health. Parents of infants with certain medical conditions should stay attuned to their child's growth patterns and physical development, as these are the prime indicators of disease-related health problems during infancy.

The most important step any parent can make in encouraging proper development is to visit a pediatrician to gauge a child's health and development. This is done largely through measurements of the child's growth curve, a ratio of weight gain to length (height). Head circumference measurements are also important to track in the first three years of life. Infants with special conditions may have growth curves that vary from the norm. Consult a pediatrician to determine if your baby is growing normally, as variations do occur.

Children with a flat growth curve—those who are not gaining adequate weight and are falling significantly in percentiles—have failure to thrive (FTT). Some children with developmental and genetic conditions are at risk for FTT. A pediatrician or a dietitian who is well acquainted with infants with special needs may be able to suggest ways to make sure the baby is receiving proper calories and nutrients.

Feeding your child with special needs

Parents should discuss any feeding problems with their pediatrician to determine if there are community resources to help manage feeding and nutrition. These resources are usually found through a local children's hospital, where they are familiar with special health needs.

While it is important for a baby to gain weight, it is equally important to maintain a healthy and varied diet with all of the right nutrients. Breastfeeding is the most perfect source of nutrition for all babies, especially those with special needs. Breast milk provides antibodies to fight disease and infection, and strengthens the bond between mother and child. Breastfeeding is important for children with neurological disorders and babies born with Down syndrome, cleft lip or palate, cardiac problems and cystic fibrosis. There are a few rare metabolic diseases (galactosemia is one) where infants cannot receive breast milk. Babies with these diseases cannot break down certain components in the breast milk and can become ill. For infants who have trouble gaining weight, a pediatrician or pediatric dietitian might recommend using fortifiers that can be added to the breast milk to ensure adequate weight gain.

A mother may have difficulties breastfeeding her baby with special needs. However, most of the time, counseling by a certified lactation consultant and some patience will achieve the goal. Mothers can also benefit from some of the products available for expressing and feeding breast milk. Some problems often associated with breastfeeding include:

- Difficulty with swallowing, associated with such neurological disorders

890

as cerebral palsy, trauma to the mouth, congenital abnormalities, or disorders with motility or movement of the upper gastrointestinal tract.

- A mother may need to offer extra kinds of physical support while nursing a child with too much or too little muscle tone.
- Infants with some diseases, like cystic fibrosis or phenylketonuria (PKU), may require special formula supplements.

The nutrient may also show promise in lowering cholesterol and heart disease risks, improving asthma and eczema, and in treatment of depression, migraines and ADD.

With some types of problems, consultation with a certified lactation consultant, pediatric occupational therapist, pediatric physical therapist and pediatric specialist related to the child's disease, may all be indicated to support the needs of baby. Special feeding devices and techniques may also be needed for these infants.

One nutrient that is particularly important in both infancy and beyond is docosahexaenoic acid (DHA), an omega-3 long chain polyunsaturated fatty acid. This fat is one of the important building blocks of the brain. During pregnancy and breastfeeding, the baby accumulates this fat from the mother and incorporates large amounts into the brain and eye tissue. This nutrient has recently been made available in infant baby formulas and the Beech-Nut First Advantage line of baby foods.

The role of omega-3 fats has been studied in a broad spectrum of diseases. DHA has been linked with lowering the risk of autoimmune diseases like multiple sclerosis, rheumatoid arthritis and diabetes. The nutrient may also show promise in lowering cholesterol and heart disease risks, improving asthma and eczema, and in treatment of depression, migraines and ADD. Of course, with any of these processes, omega-3 fats are not the complete or only answer, and should be considered along with conventional treatments under the direction of a physician.

FEEDING TIPS

Here are some feeding tips to support nutritious weight gain for infants with special needs. [Keep in mind: A pediatrician, pediatric specialist or dietitian should always be consulted first before making any dietary changes. Consult with a pediatric occupational or physical therapist for special feeding problems related to motor or physical handicaps.]

–Ask your pediatrician about infant formulas that provide more than the regular 20 calories/ounce, or some of the new formulas with DHA

–Ask your pediatrician about human milk fortifiers for babies not gaining adequately with breast milk

–Feed your child baby foods with DHA after the baby is on second-stage solid foods

–For babies over 12 months of age, instead of milk, offer Pediasure, which has more calories

–Add calorie-dense foods like avocados to solid foods

Other nutrients that are vital during infancy include vitamin A, vitamin C, folic acid, potassium and dietary fiber. These nutrients are found in various fruits and vegetables. The American Dietetic Association recommends setting a goal of five servings of fruits and vegetables a day. Following are some foods that provide these nutrients. These foods can be found in most commercial baby food lines.

Vitamin A: apricots, cantaloupe, mangos, carrots, dark leafy greens, sweet potatoes

Vitamin C: cantaloupe, oranges, strawberries, broccoli, potatoes, peas, tomatoes

Folate: strawberries, oranges, avocados, broccoli, dark leafy greens, peas

Dietary fiber: applesauce, mangos, pears, carrots, green beans, corn

Potassium: prunes, dark leafy greens, bananas, potatoes. ■

Christine Wood, M.D. has been a practicing pediatrician since 1982 and is currently in private practice with El Camino Pediatrics. She attained her undergraduate degree from the University of Detroit and her medical degree from the University of Michigan. She completed her pediatric residency at Children's Hospital of Los Angeles and received her lactation educator certification from the University of California, San Diego.

While Studley (left) helps her balance, Karolline (right) picks the colors she will use for her mural. This easy exercise helps Karolline strengthen her leg and wrist muscles.

The Just Right Challenge

By Megan Henninger

The solutions to alleviating some childhood movement problems and sensitivities are often common activities incorporated into everyday play. That is the core of The Just Right Challenge, which uses both exercise and parents to help children. The concept, originally developed for early intervention, has been integrated into physical therapy by Kelly Studley. Studley, who has her MS in physical therapy from Arcadia University in Philadelphia, PA, is a pediatric physical therapist at University Hospital in Newark, NJ, where she sees patients in the neonatal intensive care unit, the early intervention program, both the in-patient and out-patient programs and in the high-risk nursery.

Parents should first consult a pediatrician when considering physical therapy. Many therapists will not evaluate a child without a doctor's prescription due to legal and insurance restrictions. When going to a pediatrician or a therapist, it helps if parents have considered some of the following questions:

- What is the child doing?
- What does the child need to do at their age?
- Why aren't they doing it? (Is it a coordination issue? A strength issue?)

Studley asks parents to consider several factors when deciding if physical therapy is needed. She says that once a child has reached the ages of 3-5 years, it is important to watch how they fine-tune their behavior. If they're walking, parents should note what the child's gait looks like. Another factor to consider is if the child walks up on their toes. She wants them to observe if the child is stepping through with both legs and/or dragging one foot a little behind the other.

Sensory reactions can also be observed in this manner, she adds. Visually, children can have aversions to light or objects flying at their face, or have trouble focusing on a single point. Similar problems can occur with auditory stimuli.

Studley says that one such example presented itself in a group therapy session where she noticed a normally calm little boy continually flinching. After watching the boy she noticed that his response directly coincided with the symbol crashes of another child playing in the corner. Further investigation revealed that he was sensitive to loud noises. With careful introduction of music and gentle rhythms, his sensitivity improved. However, as Studley reminds, "It wasn't necessarily because of us; I think his mom's just really working with him at home." As in many other success stories, parental involvement was key to facing the challenge.

These details seem minute, but they benefit therapists and parents alike. For instance, Studley described one young girl who could get on a bicycle, get her feet on the pedals and pedal to her heart's content. However, if there was nothing holding her feet to the pedals, they came right off. She could not quite grasp the details involved in bike riding. Clips or straps that might keep her foot in place were suggested, as well as pedaling bare-foot so that the girl could get a better feel of having the pedals under her feet.

Studley explains that during the first visit it helps therapists to learn a lot about the family. What parents are seeing, their daily routine and their goals for the child are all key to creating the "just right" challenge. Because parents are just as involved as children, Studley believes that the goal should be something the parents can understand and work toward. In Studley's view, "that's what pediatric therapy is all about: it's training the parents to be the experts, because they already are the experts."

For example, a parental goal could be similar to "My child will be able to sit up to play with a toy." For a professional, this might read, "This child will demonstrate postural stability in order to demonstrate writing reactions when placed in a sitting position for bimanual play." Though they mean the same thing, parents will work on the first and ponder the second.

A good way of honing parental expertise is by learning about the system being used to evaluate your child. Knowing what a therapist is looking for may give parents an idea of what to look for in their child when determining if they are progressing or what further help needs to be provided.

Karolline works the tricycle to build her leg muscles while Studley verifies that mom understands how to help Karolline try this at home.

One of these assessment tools is H.E.L.P (Hawaii Early Learning Profile). According to Studley, it's quite popular, especially in early intervention programs, because it looks at all six areas of development. This is one of only many systems a therapist could be using, so consulting the therapist before researching assessment tools is a good idea.

"If you're making them go in some direction they don't want to go, you're going to lose them."

Studley says that certain things, such as toys and siblings, can get in the way of therapy occurring at home or in session. However, she adds that there are ways to turn them into assistants. For example, a favorite toy can be used to accomplish many tasks. A child developing balance could have to walk on a balance beam to get to the objects for play, or the toy could be put at the end of a hallway for a child to ride down on a tricycle in order to build leg strength.

Siblings can also be advantageous if they are willing to cooperate. Many children may be afraid of a new activity. Studley says that if an older brother or sister can model the exercise, showing the child that it isn't harmful, the child may find that the challenge is just right for them. Siblings can also participate in activities such as throwing , catching or providing an extra set of hands for balance activities. As long as the sibling is willing to help, inclusion can be a great asset to therapy.

Studley recalls only one thing that parents have done to try to help her that has actually been a hindrance. Sometimes a child will misbehave and this can cause a bump in the parent/therapist relationship. During such instances, therapists hope parents will take cues from them. Each therapist has a different point where they will say "enough is enough" and ask the parent to intervene on their behalf. However, the therapist needs his or her own chance to control the situation.

Studley remembers certain instances where she wasn't ready to hand over control to the parents, but they interrupted to discipline their child. She acknowledges that, "a lot of times parents are just trying to step in and be extra helpful or overly helpful because they care so much about their kid." But this can also cause problems. If the child believes that the therapist has no control over the session, the therapist could be left with a rampant child as soon as parents turn their backs.

Studley acknowledges that it is difficult for parents to watch their children struggle, but adds that therapists often feel the same way. The child has to meet their own challenges, however, through their own work and persistence. "You just have to keep reminding parents that because their child is working so much harder than a typically developing child to do this, any kind of effort that they put into the task is a great thing," Studley says. "So, even if they're not doing exactly what we want them to do, if they're trying to get there that's still a movement in the right direction, so we still need to say, 'That's a good job!'"

Studley also advises professionals to be aware of when they're pushing children too hard. "If you're making them go in some direction they don't want to go, you're going to lose them," reminds Studley. With sessions that can last anywhere from 30-60 minutes, it is difficult to keep children interested.

Studley explains that by letting the child lead the session, it can be done. "If they start to whimper they can go see mom, have some juice, have a cracker,

continued on page 28

continued from page 27

or we'll just do something that backs off a lot. Because you don't really want to push them over the edge to the point where they're like, 'this is too hard. I don't wanna do this.' Because the next time I walk into the room, I become the crazy lady who forces them to do things." The challenge has to be just right for the child in terms of both difficulty and duration.

Therapy is not a quick solution, but it can be a fun challenge. Through purposeful play everyone can be included and no one child has to face the climb alone. The "Just Right Challenge" describes more than simply finding the right activity to strengthen a child's muscles. It reflects the supporting family and friends who help to achieve it, doing what they can to make it "just right."

Karolline takes a break while Studley labels her pictures in both English and Portugese.

"IF PLAY WERE GOING TO FIX A CHILD, THEN THE CHILD WOULD BE ABLE TO FIX THEMSELVES"

This is one of the key themes that Studley offers parents. However, the solutions to possible problems are often common activities incorporated into everyday play. The following are some suggestions that should not only be fun for your child but also help them build basic skills:

SKILL: SITTING UP

What parents can do: "Consider ways of getting the child into a sitting position where they are reaching forward for the toy," says Studley. This both amuses the child (because of the toy) and makes it easier for them, as it is easier to keep one's balance while leaning forward. While the child is leaning forward, sit behind them such that your legs help support them. Gently move the toy to one side or another, so that should the child fall, they fall into a parent's leg. Repetition of this will help a child understand that there is a limit to where their balance needs to be. They can then learn their boundaries and how to come back up from that position.

SKILL: CRAWLING

What parents can do: Crawling may be a problem if a child does not have enough strength in their arms to carry their own weight. By getting a parental arm underneath the child to help support them, the weight their arms and legs have to bear decreases. Often, this makes the challenge "just right" for them, allows them to get onto all fours, strengthen their arms and legs and learn how to crawl.

SKILL: STRETCHING

What parents can do: Stretching is probably one of the most important therapy techniques as it gently reminds muscles how they work. Bath time can be a great opportunity to laugh and play with a child while stretching their legs a couple of times. Or practice kicking and stretching their legs while watching a children's video. Mornings are also a good time, as getting children dressed provides the opportunity to give a few tugs on arms or legs to stretch the muscles out a bit.

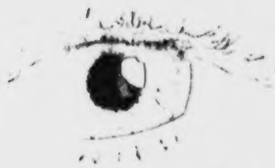
SKILL: USING BOTH SIDES OF BODY

What parents can do: "You can restrict their one side," reminds Kelly. By restricting the side used most and putting objects on the neglected side, the child is encouraged to use this otherwise dormant side. However, a child may resist, believing that it's too difficult. Sometimes, with help from mom, dad or the therapist (similar to a gentle lift at the shoulder or elbow) the exercise becomes easy enough that the child is willing to try it. This is an integral part of the "Just Right Challenge."

SKILL: ABDOMINAL MUSCLE STRENGTH

What parents can do: If the child is older than one year, lay the child on their back, with their head on a safe, padded pillow during play time. Then the game begins. Playfully offer the child the toy, so that they have to begin to sit up to get it. After they begin reaching, gently push them back onto the pillow with a playful, "Don't come get that toy." The child will normally giggle and try for the toy again. After a few repetitions of the activity, give the child the toy so that they can enjoy and relax.

BEST COPY AVAILABLE



Discover the faces of Children's Hospital

Everyday we take special care of children. From broken bones to long-term care, from infants to teens. It's our understanding of children and their families that makes us unique.

For over 80 years now, Richmond's Children's Hospital has been providing specialty pediatric care. We understand children. And what it takes to tailor our services to their individual needs.

Take for example, our Pediatric Feeding Disorders Program, one of only a few such services in the country.

Or our Inpatient Rehabilitation Program which helps children who have experienced trauma, disease or impairments return to the activities of daily life.

For adolescents who need subacute care to babies who have never seen the outside world, our Transitional Care Unit is a step toward home. And a place where parents learn to care for their child's special needs.

Discover where children come first.

Children's Hospital

Specialty Services for Children

2924 Brook Road • Richmond, Virginia 23220-1298
(804) 228-5818
www.childrenshosp-richmond.org

We accept most commercial payors, Medicaid HMO's and Medicaid.

Infant Development Specialists

PLAYING WITH BABIES, HELPING THEM GROW

By Linda S. Dingman, MA

It's Wednesday morning and my first stop is the gated community where two-year-old Susannah lives with her mom and dad. Susannah has a developmental delay, yet despite numerous blood tests and genetic studies she does not yet have a diagnosis. Next I will head downtown to work with 8-month-old Margarita, an adorable baby with Down syndrome. She lives in a tiny, one-bedroom apartment with her mother, grandmother and three brothers. Afterwards I will see handsome Zachary, who was exposed to drugs before birth. He was placed in a wonderful foster home directly from the hospital. Late in the afternoon I will visit the twins, Charlie and Andrew. The boys were born prematurely, and Charlie developed severe hypertonia. At 18 months old, he is unable to sit up. Andrew seems to be reaching developmental milestones on schedule but joins our play sessions because he is a valuable assistant and co-teacher.

WHAT IS AN INFANT DEVELOPMENT SPECIALIST?

Infant development specialists are special education teachers who work in early intervention, also called infant stimulation, usually in the client's home or occasionally in day care. They incorporate play skills and basic motor skills into their lessons and stimulate both receptive and expressive language. Some specialists work with counselors and other professionals in regional centers.

> ***If the family agrees to infant stimulation, the counselor calls me to make the referral. In some cases, the baby will receive many types of intervention, making me part of a team including an occupational therapist, physical therapist, speech therapist and, in a few cases, a behavior management specialist.***

An infant development specialist must meet specific state standards. I hold a state credential in special education for the severely handicapped and am self-employed, but some infant development specialists work through agencies that have both in-home and center-based programs, such as early intervention preschools.

HOW ARE CHILDREN REFERRED TO ME?

Children may be referred to a regional center for specialists by their pediatrician or another professional who is concerned about their development. Usually an occupational therapist and a regional center counselor visit a child's home to evaluate the baby. They use assessment tools in their evaluation, such as the Bayley Scales of Infant Development II and the

Receptive-Expressive Language Scales, and also make clinical observations of muscle tone and range of motion. If the family agrees to infant stimulation, the counselor calls me to make the referral. In some cases, the baby will receive many types of intervention, making me part of a team that includes an occupational therapist, physical therapist, speech therapist and, in a few cases, a behavior management specialist.

TRACKING THE CHILD'S PROGRESS

In order to track progress, I must observe the baby's skills as we play and gather information from the parents. After a few weeks, I write an initial report which incorporates the birth and medical history and provides a portrait of the child's personality, likes and dislikes, needs and abilities. I continue to work with the child once or twice a week, taking notes to track the newest achievements and any changes in health or living conditions. After four to six months I am required to write a progress report either requesting an extension of my authorization to work with the child or recommending that s/he make the transition to an appropriate preschool program. In some cases, the child does not go to a program outside of the home, either because s/he is not ready or because it is not what the parents wish. No matter what, I only stay with the child until age three, after which the family must find another form of support. Some children who were originally considered to be at risk for developmental delays will have caught up and no longer qualify for help. Others will qualify for special education in public school; I am usually involved in helping the family make that decision.

WHAT HAPPENS DURING A PLAY SESSION?

Upon arriving at a client's home, I sit on the floor with the child. Each week I bring a different selection of toys and other objects. My toy bag designed for babies holds rattles, simple cause-and-effect toys with lights and music, and a collection of interesting textures such as silk, pot scrubbers, velvet and a sponge. Some weeks I bring jars of good things to smell, such as garlic, oregano, cloves, cinnamon, eucalyptus and perfume. The toddler bag has shape-sorters, simple puzzles, blocks, nesting cups and role-playing toys such as cars and trucks or dress-up clothes and a tea set. In each bag I include colorful board books and a ball. I start each play hour with a "Hello" song and end with blowing bubbles. To facilitate language development, I use sign language whenever possible. Some activities are seasonal: at Halloween we carve pumpkins; at Christmas time we make a simple gift for the family; at Easter we dye a hard-boiled egg; and in the summer we do a lesson about fish and seashells. Whenever possible, I bring along an age-appropriate art activity. If the child is upset, I sing lots of songs. Young children learn best with multi sensory, language-rich activities paced to suit their temperament and age.

HOW DO I WORK WITH THE FAMILIES?

Many of my clients treat me as a part of the family. Although I am a professional and try to maintain objectivity, by sitting on the living room floor twice a week for a year or more I get to know the cat's name, welcome the new baby, and help translate those mysterious governmental forms that come in the mail. Susannah's grandmother lives on the east coast, so her mom often asks me for practical advice. Margarita's family doesn't own a refrigerator, but her medicine must be refrigerated, so I am working to link the family with a local church that sells good used appliances at very low cost. I enjoy locating resources for families and have developed an extensive list of local agencies, publications and web sites that are useful.

OPTIMAL LEARNING ENVIRONMENTS

Parents often want to stay with the child while I work. I welcome their involvement and can offer suggestions for successful learning activities. On the other hand, in Charlie and Andrew's home the hour that I play with the boys is a necessary break for mom. It may be the only chance she has to fold the laundry, start dinner or collect her thoughts.

continued on page 32

My toy bag designed for babies holds rattles, simple cause-and-effect toys with lights and music, and a collection of interesting textures such as silk, pot scrubbers, velvet and a sponge.

When a family feels that they are the head of a team and can work in concert with the regional center and all the specialists in their child's life, the results are often amazing.

continued from page 31

Although brothers and sisters are welcome to participate in my lessons, occasionally a jealous or unhappy sibling makes learning impossible. Sometimes I can bring along a special toy that will appeal to the older child so that everyone benefits.

SOMETIMES IT DOESN'T WORK OUT

A family sometimes decides after a few sessions that they do not want infant stimulation for their baby. Although their expressed dissatisfaction can help me grow as a teacher, I worry about the child. Occasionally the parents focus their grief and anger over having a child with delays on me. In other cases, there are very serious problems in the home, and the family does not want an outsider in their lives at that point. The parents' wishes are always respected, and counselors work with the family to find the services that will best fit their needs.

TEAMWORK AND RESULTS

Parents know more about their children than anyone else does. When a family feels that they are the head of a team and can work in concert with the regional center and all the specialists in their child's life, the results are often amazing. Some children reach milestones in sudden spurts. Others acquire new skills slowly but surely. Some of my clients have seemingly made no progress at all until they undergo surgery or a change is made in medication. Once they are truly well—often for the first time in their lives—they make splendid strides.

SAYING GOODBYE

Next month, Zachary will be given his diploma. When I met him, he was a cranky baby who was months behind schedule. Now, he is an engaging little boy, and everyone's favorite. Although I will miss him, I already have other clients waiting for me to fit them into my schedule. EP

Linda Dingman, MA holds a California teaching credential in special education. She was Head Teacher at the Infant-Toddler Development Center at California State University—Dominguez Hills until 1996, when she became a self-employed infant develop-

HDIS
Convenient Home Delivery of Bladder Control Products

Try 20 briefs for only $9.95

Youth & Small Sizes

Not sure which brief is best for your child? Then give 5 of the best known brands a try for just $9.95. Our Youth/Small Brief Sample Pack includes two youth and two small of the following briefs.

- Attends®
- Tranquility® Slimline
- Tranquility® All-Through-the-Night
- TENA® Ultra
- SuretyS Wings® Choice Plus*
- Molicare® T-Shape*

*Available in small only

Call for a sample pack today!
1-800-2MY-HOME®
(1-800-269-4663)

"We're here to help make your life easier."
- Mary

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

©2002, HDIS 024-132

Circle #38 or visit www.eparent.com/adinfo

898

Justin Dart, Jr.
Legend in Disabilities Advocacy

Best known as the father of the Americans with Disabilities Act (ADA), Justin Dart, Jr. recently passed away at age 71.

Dart was a great supporter of people with disabilities in America and around the world, and worked for more than fifty years to improve awareness and relevant legislation. He is credited with having a significant role in enacting the ADA which was signed into law by President Bush in 1990.

Born in Chicago in 1930, Dart's advocacy began shortly after he contracted polio at age 18 and became wheelchair-dependent. Passionate about civil rights for many groups, he organized an "integration club" at the University of Houston and continued to support rights for women, gays, lesbians and people of all races throughout his career.

Dart was also an entrepreneur, and founded three successful corporations. One of them, Japan Tupperware, Ltd., grew from four employees to 25,000 within the first two years of its existence. Dart used his corporate ability to support his political beliefs by employing women and people with disabilities when others would not.

The list of awards that Dart has received over the years is pages long. Some of the more notable include:

- ☐ Induction into the Disability Hall of Fame (1987)
- ☐ The World Congress of Rehabilitation
- ☐ International, President's Award (1992)
- ☐ The National Parent Network on Disabilities, Outstanding Leadership Award (1994)
- ☐ The National Council on Independent Living, for outstanding contributions to civil rights (1996)

In 1998 President Clinton awarded Dart the Medal of Freedom, the country's highest civilian honor. Dart has also served numerous government appointments, including Chairperson of the President's Committee on the Employment of People with Disabilities.

Dart was known for his cowboy hat and boots, as well as for his tenacity and relentlessness. He has visited every state in the country at least five times, mainly to promote the passage and implementation of the ADA. He has often been compared to Martin Luther King, Jr. because of his leadership and commitment to civil rights.

Dart is survived by his wife, Yoshiko, and five daughters.

Shopping solo

Chase, a 19-year-old with autism, can now tolerate the noise and overhead music in the store. He's learned to ignore the candy and chips, to choose nutritious foods without the help of props or pictures. Back at Heartspring, he neatly puts the groceries away and sets the table. After dinner he washes and dries the dishes. With only a little supervision. And with a lot of pride.

HEARTSPRING™
SCHOOL
Finding New Ways for Learning
8700 East 29th Street North • Wichita, Kansas 67226
call 1-800-835-1043
www.heartspring.org

Circle #20 or visit www.eparent.com/adinfo

Universal Newborn Screening AN UPDATE

By Julia Steele

While universal newborn screening has obvious benefits where health and disease prevention are concerned, the implementation of such programs comes with a certain price tag attached. The question in this case is the same as in most others when it comes to governmental issues: who is going to pay for it?

Newborn screening is a process by which certain disorders can be tested for and potentially identified in the first 24-48 hours after birth. It is not a new concept; the first screening test was developed by Dr. Robert Guthrie at the University of Buffalo in 1961. Just five years later, his test for phenylketonuria (PKU) had been adopted on a mandatory basis by every state and the District of Columbia. Other newborn screening programs have fallen into place as well. For instance, universal hearing screening is supported by the American Academy of Pediatrics (AAP) and the Maternal and Child Health Bureau of HRSA (Department of Health and Human Services).

Now, although we still do not have the ability to screen for every existing metabolic disorder, there are at least 30 disorders that can be identified. This has been made possible largely by the development of a technology called tandem mass spectrometry (MS/MS). While it cannot screen for all metabolic problems, MS/MS is very effective in identifying fatty acid, amino acid and organic acid disorders.

It is up to each state to set its own regulations about which tests to mandate or make available on a supplemental basis. Only a few tests have been universally adopted. All 50 states and the District of Columbia screen newborns for PKU and congenital hypothyroidism; 49 states screen for galactosemia; and 42 states screen for sickle cell anemia. Beyond that, there is quite a disparity among states; some require only three tests while others require more than twenty, and not every test is available in every state (see the charts on pages 36-37).

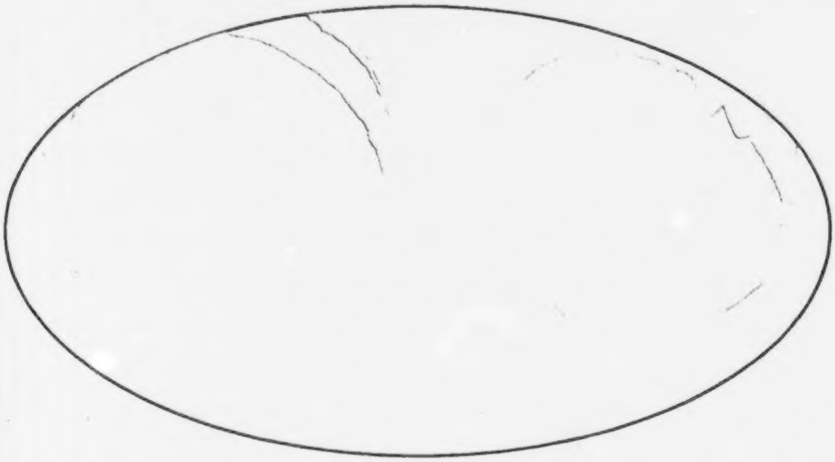
Many states are in the process of independently increasing their newborn screening programs, since new technology is making testing easier and more economical. At least 15 states have become interested in MS/MS technology and have implemented pilot projects to determine what kinds of screening programs are most worthwhile. In states where MS/MS is not used, parents can order test kits from private labs to be sent back for MS/MS screening. Still, there are many people who believe that universal newborn screening should be mandated; that is to say, that every test should be available in every state.

This is much more easily said than done, however, because each state also determines what, if any, fee to charge for screening. Some states choose to bill parents directly, while others pay for testing with tax dollars or other funds. This is one reason why some states have such limited screening programs.

In many cases where parents are billed, their insurance companies will cover the cost. Some states even require that health insurance plans cover newborn screening fees in their state (e.g., Arkansas, California, Missouri, Texas). But no matter where the money comes from, one thing is clear: In order to establish any kind of universal program, there must be a way to pay for it.

Many variables determine the cost of screening. For example, some hospitals use state or regional labs to run the tests, while others send samples away to private labs. Also, there are different costs for each type of test, so total screening cost can vary depending on which tests are performed. In March 2001, PricewaterhouseCoopers conducted a survey on newborn screening showing that the average cost of processing specimens for the 28 states responding was $18 (the median was $15). In cases where states do not cover this cost themselves, screening fees tend to be inflated in order to help cover overhead costs.

The development of MS/MS has helped to reduce the price of newborn screening, since it can test for nearly 30 different disorders all at once, including conditions such as PKU, maple



syrup urine disease, and biotinidase. The processing only takes about two minutes, though it does take longer to read the results. This means that the system can process large numbers of specimens, which would be necessary for universal screening. But because it cannot screen for all disorders, some tests still have to be run separately, keeping the cost up.

Another issue involved in cost analysis is the return of false positives. Typically, the screening process will return either a "normal" or an "abnormal" result. An abnormal test does not mean that the disorder is definitely present, just that follow-up testing is required. Again, MS/MS is improving the screening process, reducing the rate of false positives seen with traditional methods from about 1.5 percent to about 0.26 percent.

Of course, follow-up testing means an additional financial cost. And since many of these disorders can present themselves rapidly after birth, even within hours, it is imperative that follow-up testing be done as soon as possible. Before a given state can expand its screening program to include more tests, it must ensure that it has adequate follow-up procedures available for the tests it already provides.

Many of the diseases for which newborns can be screened are actually quite rare. In the majority of abnormal returns, further testing reveals that there is actually nothing wrong. Still, the cost of universal screening is negligible compared to the cost of leaving these disorders undetected. Many of the conditions screened for can result in severe mental retardation or even death if left untreated. You can't put a price on the life of your child.

It is important to remember, however, that there is more to handling a disorder than simply screening for it. None of these disorders is preventable, though all are treatable. Once a metabolic disorder is identified in a newborn, that child will likely need medication and a special diet to control the condition, sometimes for the rest of the child's life. These treatments can be very expensive.

The costs associated with universal newborn screening may not all be economic, either. There are emotional and societal issues to consider as well. For instance, not all parents prefer to know ahead of time that their child will develop an incurable condition. There are also the emotional costs that come with false positive test results. And while newborn screening is able to detect many metabolic problems early on, a normal test result does not guarantee that problems won't develop in the future.

Answers to these problems may be provided if screening programs are carefully developed. If parents prefer not to know the outcome of their child's test, give them the option not to read the results. To curb the anxiety that comes with an abnormal return, let healthcare providers properly educate expectant parents about the screening process, including the tendency of abnormal results to be misleading. Also, provide parents with literature about some of these disorders and signals they can watch for, should something develop in the future.

Universal newborn screening is an important issue that is getting a lot of attention. MS/MS and other advances have made such a program much more feasible in recent years, but the need for specialized training and the great expense of the machines are still hurdles to be overcome before universal screening is a reality. It may just be a matter of time while technology continues to improve and provide more affordable testing methods. In the meantime, it is important for parents and physicians to make each other aware of the issues, and to weigh the costs involved. EP

For more information on universal newborn screening, see EP's earlier articles on universal newborn screening in Aug., Sept. and Oct. '00, which are reprinted in our monograph, "Universal Newborn Screening." Other articles appeared in Aug. and Sept. '01. Archived articles can be found at http://www.eparent.com

The following web sites contain more information on newborn screening:

http://www.newbornscreening.com/

http://genes-r-us.uthscsa.edu/

http://www.savebabies.org/ (formerly www.tylerforlife.org)

To read the PricewaterhouseCoopers study, "Newborn Screening Programs: An Overview of Costs and Financing," go to: http://www.modimes.org/HealthLibrary/

Table 1. U.S. National Screening Status Report

The National Screening Status Report lists the status of newborn screening in the United States. All infants in a state must be screened in order for a dot to be added.

State	PHE	CH	GAL	MSUD	HCY	BIO	SCD	CAH	MS/MS	Other
Alabama	•	•	•				•	•		
Alaska	•	•	•	•		•	a	•		
Arizona	•	•	•	•	•	•	•	•		
Arkansas	•	•	•				•			
California	•	•	•				•		ms/ms	
Colorado	•	•	•			•	•	•		2
Connecticut	•	•	•	•	•	•	•	•		2a
D.C.	•	•	•	•	•		•			5
Delaware	•	•	•				•	•		
Florida	•	•	•				•	•		
Georgia	•	•	•	•	•		•	•		3
Hawaii	•	•	•	•		•	•	•	ms/ms	
Idaho	•	•	•	•		•				
Illinois	•	•	•			•	•	•		
Indiana	•	•	•	•	•	•	•	•		
Iowa	•	•	•	b	b	b	•	•	ms/ms	
Kansas	•	•	•				•			
Kentucky	•	•	•				•			
Louisiana	•	•	•			•	•			
Maine	•	•	•	•	•	•	•	•	ms/ms	
Maryland	•	•	•	•	•	•	•	•		3
Massachusetts	•	•	•	•	•	•	•	•	ms/ms	1,2a
Michigan	•	•	•	•		•	•	•		
Minnesota	•	•	•	b	b		•	•	ms/ms	
Mississippi	•	•	•				•	•		
Missouri	•	•	•				•	•		
Montana	•	•	•			a	b	a	ms/ms	2a
Nebraska	•	•	•	a	a	•	•		ms/ms	
Nevada	•	•	•	•		•	•			
New Hampshire	•	•	•	•	•		a			1
New Jersey	•	•	•	•		•	•	•	ms/ms	2
New Mexico	•	•	•			•	•	•		
New York	•	•	•	•	•	•	•			4
North Carolina	•	•	•	•	•		•	•	ms/ms	
North Dakota	•	•	•				a	•	ms/ms	
Ohio	•	•	•	•	•		•		ms/ms	
Oklahoma	•	•	•				•			
Oregon	•	•	•	•		•	•			
Pennsylvania	•	•	•	•			•	•		
Rhode Island	•	•	•	•	•	•	•	•		
South Carolina	•	•	•				•	•	ms/ms	
South Dakota	•	•	•	a	a		a		ms/ms	
Tennessee	•	•	•				•	•		
Texas	•	•	•				•	•		
Utah	•	•	•				•			
Vermont	•	•	•	•	•	•	•			
Virginia	•	•	•	•	•	•	•	•		
Washington	•	•					•	•		
West Virginia	•	•	•				a			
Wisconsin	•	•	•	b	b	•	•	•	ms/ms	2
Wyoming	•	•	•			•	•			2

PKU-Phenylketonuria
CH-Congenital Hypothyroidism
GAL-Galactosemia
MSUD-Maple Syrup Urine Disease
HCY-Homocystinuria
BIO-Biotinidase
SCD-Sickle Cell Disease
CAH-Congenital Adrenal Hyperplasia
MS/MS-Tandem Mass Spectrometry Screening

a-selected population, pilot program, or planning underway; **b**-universal pilot

1-Toxoplasmosis; **2**-Cystic Fibrosis; **3**-Tyrosinemia; **4**-HIV; **5**-G6PD

Source: National Newborn Screening & Genetics Resource Center

Updated 05/08/02

BEST COPY AVAILABLE

Table 2. U.S. National Screening Status Report, MS/MS

The National Screening Status Report lists the status of newborn screening by MS/MS in the United States. All infants in a state must be screened in order for a dot to be added.

								State							
Disorder	**CA**	**HI**	**IA**	**ME**	**MA**	**MN**	**MT**	**NE**	**NJ***	**NC****	**ND**	**OH**	**SC**	**SD**	**WI**
Fatty Acid Oxidation Defects															
Carnitine Palmitoyl Transferase Deficiency Type I (CPT-1)	a	a	a							•					
Carnitine Palmitoyl Transferase Deficiency Type II (CPT-2)	a	a	b	a	a	b	a	•		•				a	•
Carnitine/Acylcarnitine Translocase Deficiency (CAT)	a	a	b			b		a		•				a	
Long-Chain Hydroxy Acyl-CoA Dehydrogenase Deficiency (LCHAD)	a	a	b	a	a	b	a	a		•				a	•
Multiple Acyl-CoA Dehydrogenase Deficiency (GA-II)	a	a	b	a	a	b	a	a		•				a	•
Short-Chain Acyl-CoA Dehydrogenase Deficiency (SCAD)	a	a	b	a	a	b	a	a	•	•				a	•
Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)	a	a	•	•	•	b	a	a	•	•	b	•	•	a	•
Trifunctional Protein Deficiency	a	a	b			b		a						a	
Very-Long-Chain Acyl-CoA Dehydrogenase Deficiency (VLCAD)	a	a	b	a	a	b	a	a	•	•				a	•
Long-Chain Acyl-CoA Dehydrogenase Deficiency (LCAD)	a	a	b		a	b			•	•					
2,4 Dienoyl-CoA Reductase Deficiency			b				a								•
Organic Acidemias															
Glutaric Aciduria Type I (GA-1)	a	a	b	a	a	b	a	a		•				a	•
3-Hydroxy-3-Methylglutaryl CoA Lyase Deficiency (HMG)	a	a	b	a	a	b	a	a		•				a	•
Isobutyryl-CoA Dehydrogenase Deficiency	a	a	b					a						a	
Isovaleric Acidemia (IVA)	a	a	b	a	a	b	a	a		•		•		a	•
Malonic Aciduria			b					a						a	
3-Methylcrotonyl-CoA Carboxylase Deficiency (3-MCC)	a	a	b	a	a	b	a	a		•				a	•
Methylmalonic Acidemia (MMA)	a	a	b	a	a	b	a	a		•		•		a	•
Mitochondrial Acetoacetyl-CoA Thiolase Deficiency (3-Ketothiolase)	a	a	b	a	a		a	a		•				a	•
Propionic Acidemia (PA)	a	a	b	a	a	b	a	a		•		•		a	•
2-Methylbutyrl-CoA Dehydrogenase Deficiency	a	a	b					a						a	
Other Amino Acidemias															
Argininemia	a	a	b	a	a	b		a						a	
Argininosuccinate Lyase Deficiency (ASA)	a	a	b	a	a	b		a	•	•		•		a	b
Citrullinemia	a	a	b	a	a	b		a	•	•		•		a	b
Hyperammonemia, Hyperomithinemia, Homocitrullinuria (HHH)			b	a	a			a						a	
Nonketotic Hyperglycinemia			b					a						a	
5-oxoprolinuria			b					a						a	
Tyrosinemia Type I	a	a	b	a	a	b		a		•				a	b
Tyrosinemia Type II	a	a		a	a			a		•				a	

CA-California, **HI**-Hawaii, **IA**-Iowa, **ME**-Maine, **MA**-Massachusetts, **MN**-Minnesota, **MT**-Montana, **NE**-Nebraska (through Baylor), **NJ***-New Jersey (testing mandated for January 1, 2002 but not yet in place), **NC****-North Carolina (full screening with ms/ms mandated, with disorders to be delineated as they are identified), **ND**-North Dakota (through Iowa), **OH**-Ohio, SC-South Carolina, **SD**-South Dakota, **WI**-Wisconsin

a-selected population, limited pilot program, or by request; **b**-universal pilot

Source: National Genetics Screening & Genetics Resource Center. Updated 05/03/02

BEST COPY AVAILABLE

World Congress & Exposition on Disabilities

October 3-5, 2002 ◆ Orlando, Florida

EDUCATIONAL SPONSORS

Allergan, Inc.
American Academy for Cerebral Palsy
  & Developmental Medicine (AACPDM)
American Academy of Pediatrics
American Association for Active Lifestyles & Fitness (AAALF)
Association of University Centers on Disabilities

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

Over 200 Conference Sessions

Over 250 Product & Service Providers

Sports & Recreation Activity Center

Employment Pavilion

Assistive Technology Learning Center

Employment Symposium
Sponsors

VR Florida Department of Education

awi

MEDIA SPONSORS

Active Living magazine
Disabled Dealer of Southeast
EP (Exceptional Parent)
InMotion
New Mobility
PALAESTRA
Paraplegia News
Sports 'N Spokes
Teaching Exceptional Children
Today's Caregiver
We Media

SUPPORTING ORGANIZATIONS

AAMR
America's Athletes with Disabilities
Amputee Coalition of America
Angelman Syndrome Foundation
Autism Recovery Network
Autism Society of Florida
Council for Exceptional Children
Easter Seals
Families of S.M.A.
Family C.A.F.E.
Family Voices
Florida Alliance for Assistive Service
  and Technology, Inc. (FAAST)
Florida Association
  of Rehabilitation Facilities
Florida Children's Forum/Central Directory
Florida Institute for Family Involvement (FIFI)
Muscular Dystrophy Family Foundation
National Family Caregivers Association
National Multiple Sclerosis Society
National Perinatal Association
RESPECT of Florida
Southeast Disability & Business Technical
  Assistance Center
Special Olympics
Spina Bifida Association of America
TASH
UCP
United Parents' Syndicate on Disabilities

BEST COPY AVAILABLE

(877) 923-3976 x832 ◆ wcdinfo@wcdexpo.com ◆ www.wcdexpo.com

HAB H.A. BRUNO, LLC

EP Exceptional Parent

sigma-tau PHARMACEUTICALS, INC.

EP Foundation for Education, Inc.

Circle #65 or visit www.eparent.com/adinfo

Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—October 3 - 5, 2002

LOCATION:
Orange County Convention Center—Orlando, Florida

***A UNIQUE GATHERING*—**A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract **physicians • families • direct support professionals • people with disabilities • allied health care professionals • educators • adapted physical education specialists.**

TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.

SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more, hosted by America's Athletes with Disabilities.

EMPLOYMENT SYMPOSIUM AND PAVILION: Human resource managers will discuss career opportunities, sponsored by Florida's Agency for Workforce Innovation and the Florida Department of Education, Division of Vocational Rehabilitation Services (VRS) and McDonald's Corporation.

ASSISTIVE TECHNOLOGY LEARNING CENTER: Produced by FAAST. Computer Stations designed for hands-on education and fun.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.

CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment.

- All WCD attendees can experience discussions by internationally renowned experts specializing in neurology, orthopedics, pediatrics, internal medicine, family medicine, physical medicine, epidemiology, DDS, movement disorders, mitochondrial and metabolic disorders, neonatology, seizure disorders, autism, and other disabilities and chronic conditions as well as general practitioners.
- CME and CEU accreditation, through approved accreditation institutions, will be offered for a dozen disciplines.
- Hear parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.
- An Employment Symposium produced in conjunction with Florida's Agency for Workforce Innovation and the VRS will offer sessions for people with disabilities, their families and employers.
- Learn from special education professionals what is going on in classroom environments.
- Participate in adapted physical education activities and seminars.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

October 3-5, 2002 • WORLD CONGRESS & EXPOSITION ON DISABILITIES

EXCITING NEW FEATURES TO HIGHLIGHT WCD IN OCTOBER!

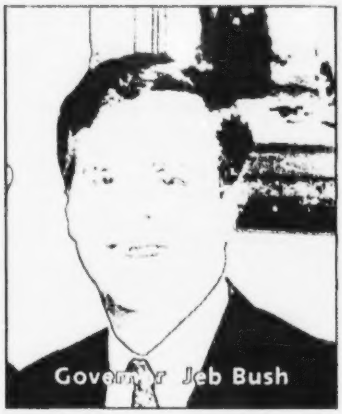
The World Congress & Exposition on Disabilities (WCD) is fast approaching. Coming October 3-5, 2002 to the Orange County Convention Center, this event has matured into an event which producer H.A. Bruno, LLC and all the sponsors and supporters can be proud of. The WCD is sponsored in association with EP (Exceptional Parent) Magazine, and Sigma Tau Pharmaceuticals as a gold sponsor. Over 40 national and local organizations, along with 11 publications, support and promote the event throughout the year.

The conference program, developed by the EP Foundation for Education, Inc., is sponsored by UPMC Health System, University of Pittsburgh School of Medicine Center for Continuing Education in the Health Sciences, and supported by EP (Exceptional Parent) Magazine and the National Institute of Health's Office of Rare Diseases. The program has expanded to over 200 sessions including many sessions for people with disabilities and their families, medical professionals, educators and many others. Included this year are over 60 adapted physical activity sessions and more than 50 topics specific to employment for people with disabilities.

The exhibit floor of the WCD will have more product and service providers than ever before. "Companies that exhibited with us previously are back again, and through word of mouth over the last two years many more new exhibitors are participating," said Director of Sales Rich DelGiorno.

In addition to the increase in educational seminars and the exhibit floor, numerous special features will be offered at this year's show in our new location, Orlando, Florida.

SCHEDULED SPECIAL GUEST SPEAKER, GOVERNOR JEB BUSH


Governor Jeb Bush

On Friday, October 4th at 5:30 p.m., Governor Jeb Bush will take time out of his very busy schedule to present a keynote address at the WCD. Governor Bush earned a bachelor's degree in Latin American Affairs from the University of Texas at Austin. He came to Florida from Texas in 1980 as a businessman with a small family and big dreams of opportunity. He later served as Florida's Secretary of Commerce where he ardently promoted Florida's business climate worldwide. Following an unsuccessful bid in 1994 for governor of Florida, Bush founded a think tank, the Foundation for Florida's Future and helped launch the state's first charter school in Liberty City.

Governor Bush was elected the 43rd governor of the state of Florida on November 3, 1998. During his first three years in office, Governor Bush and his administration have honored their commitments to the people of Florida to improve public schools; provide substantial, broad-based tax relief; fight the battle against illegal drugs; protect the natural environment; get tough on criminals who use guns; and reform social services to better serve children, elders and those with disabilities.

DENTAL, VISION AND SPEECH-LANGUAGE SCREENINGS

Nova Southeastern University's College of Dental Medicine and College of Optometry faculty and students will conduct complementary dental and vision screenings, while the Fischler Graduate School of Education will provide screenings for speech-language and communication disorders. And all right on the exhibit floor.

CONTINUING EDUCATION CREDITS

UPMC HEALTH SYSTEM

CME and CEU accreditation is being offered through the University of Pittsburgh School of Medicine. CEU accreditation has been awarded for nurses (12 hrs), athletic trainers (16 hrs), speech-language pathologists (1.2 hrs), social workers (16 hrs) and OB/GYNS (10 cognate hrs). CEUs for OTs, PTs, recreational therapists and family practitioners are pending. CEU accreditation for educators (1.3 hours) is available through the Council for Exceptional Children. The conference program is developed by the EP Foundation for Education, Inc., a 501(C)3 not-for-profit organization, with the assistance of EP (Exceptional Parent) Magazine. (For accreditation updates, please call 877-923-3976 x 852.)

WEDNESDAY WORKSHOPS

Even though the exhibits and conference program begin on Thursday, October 3, three adapted activity workshops have been scheduled for Wednesday, October 2. "Physical Fun for Everyone," addressing modifications and instructional ideas for children's activities, and "The Top Down Planning Model," which will focus on the implementation of Individualized Education Program goals and objectives for physical education, will take place in the afternoon. The evening session, "The Circle of Rings—Collaboration between Teachers, Therapists and Families," will be a lively panel discussion on family issues related to adapted physical activity. All sessions are participatory and attendees should come dressed accordingly.

EMPLOYMENT SYMPOSIUM AND PAVILION

Florida's Agency for Workforce Innovation and the Florida Department of Education, Division of Vocational Rehabilitation Services are sponsoring a 55 session Employment Symposium for those seeking employment as well as potential employers, and an Employment Pavilion, with dozens of companies looking to hire individuals with disabilities, sponsored by McDonald's Corporation.

we love to see you smile

ELECTION DAY

It is important that every American eligible to vote take advantage of the opportunity. So get out and make your vote count. However, you can not vote if you are not registered. Voter registration will take place at the WCD. This opportunity comes around but once every four years. Be Heard.

WHEELCHAIR SERVICE AND REPAIR

Custom Mobility will offer up their expertise for emergency service to manual and power wheelchairs to keep them mechanically safe, including flat tires, tightening wheels, wheel locks, etc. This service is free of charge to all WCD attendees. "We are looking forward to sponsoring a service center at this year's World Congress and Exposition on Disabilities. We will be available for emergency service throughout the event. If you have any questions about the servicing and maintenance of your wheelchair we will be glad to discuss this with you," said Customer Service Manager Robert Kriebel.

EXHIBITORS

A.C.F. Environmental
AAMR-American Association On Mental Retardation
Able Pathways Consulting
Accessibility Services, Inc.
Acorn Stairlifts Inc.
Advanced Respiratory
Allen Institute
Allergan, Inc.
Alternatives for Special Kids
Amcar Motors Corp.
America's Athletes with Disabilities
American Association for Active Lifestyles & Fitness (AAALF)
Anew International
Angelman Syndrome Foundation
Anne Carlsen Center for Children
Applied Nutrition Corp.
Aquatic Access Inc.
Aurora Ministries
Autism Recovery Network
Autism Society of Florida
B Wells Promotions
Barrier Free Lifts
Best Bath Systems
Betacom Corporation
Beyond Adversity TV
BeyondHearingAids
Blue Cross Blue Shield of Florida
Bodypoint Designs Inc.
BodySense
Bunni - Steps Design Innovation and Concepts, Inc.
Cambrooke Foods
Canine Companions for Independence
Challenge Publications
Children's Medical Services
Christopher & Dana Reeve Paralysis Resource Center
Cloister Creek
Columbia Medical
Communicating Partners Center
Communication Access Network
Concord Elevator Inc.
Continental Press/Seedling Publication
Convaid Inc.
Council for Exceptional Children
Crotched Mountain
Custom Mobility, Inc.
Cyberonics, Inc.
David Mandt & Associates
DBH Attachments, Inc.
Defense Threat Reduction Agency
Department of Veteran Affairs
Destiny Futurequest, Inc.
Dietary Specialties
Disabled Dealer Magazine
Disney Worldwide Services, Inc.
Dolphin Human Therapy
Downi Creations Inc.
Driving Aids Development Corp.
Drymids
Dynavox Systems LLC
Dystonia Medical Research Foundation
Easter Seals
Economic Mobility
Effective Communication Solutions, Inc.
ElDorado National
Emergency Caller Systems/Peat
English Avenue Industries
EP (Exceptional Parent) Magazine
Epilepsy Foundation
EP Foundation for Education
EP Library
Euromed Rehabilitation Center
Euro-Peds
Families of SMA
Family C.A.F.E.
Family Voices
FedEx Services
Federal Medicare Agency
Fischler Graduate School of Education
Flaghouse
Florida ADA Leadership Network
Florida Alliance for Assistive Service and Technology, Inc. (FAAST)
Florida Association of Rehabilitation Facilities
Florida Children's Forum/ Central Directory
Florida Independent Living Council
Florida Institute for Family Involvement (FIFI)
Florida Spinal Cord Injury Resource Center
Ford Motor Co.
Freedom Concepts Inc.
Gabby's
Gemma B. Publishing, Inc.
General Motors Mobility
Genzyme
Guldmann Inc.
Harry Klitzner Company
Health South
Heartspring School
Hewlett Packard
Hoveround Corporation
Hyperbaric Therapy Center
Invacare
Island Dolphin Care, Inc.
JayJo Books, LLC
Judge Rotenberg Educational Center
KayJae Manufacturing Co., Inc.
Kinetech, Inc.
League School of Greater Boston for Asperger/ Autism Disorders
Learning Strategies, Inc.
LNR Publications
Magitek.com, LLC
McDonald's Corporation
Mead Johnson
Merrill Lynch & Co. Inc.
Metroplex Voice Computing Inc.
Mind Wing Concepts Inc.
Moving Solutions
Mulholland Positioning Systems Inc.
Muscular Dystrophy Family Foundation
MyMedMart, Inc.
National Disability Sports Alliance
National Family Caregivers Association
National Institutes of Health
National Multiple Sclerosis Society
National Perinatal Association
New Mobility Magazine
NewHope Generation, Inc.
NIH, Office of Equal Opportunity & Diversity Management
NISH
North Oakland Medical Centers
Nova Southeastern College of Dental Medicine
Nova Southeastern College of Optometry
Ocean Hyperbaric Neurologic Center
Office of Civil Rights, International Broadcasting Bureau
Office of Rare Diseases, NIH
PALAESTRA
Pathways Development Group, Inc.
Perkin Elmer Life Sciences
Permobil
Possibilities Foundation, Inc.
Prairie View Industries, Inc.
Prentke Romich Company
Pride Mobility Products
Rare Disease Therapeutics, Inc.
Remedia Publications
RESPECT of Florida
Ricon/Concord
Rifton Equipment
Ross Products Division/ Abbott Laboratories
Sammons Preston
Scooter Lift Mfg Co.
Search Beyond Adventures
Shire US Inc.
SHS North America
Sigma Tau Pharmaceuticals, Inc.
Social Security Administration, Office of Disability
Southeast Disability & Business Technical Assistance Center
Southpaw Enterprises, Inc.
Special Olympics
Sunrise Medical
SureHands Lift and Care Systems
T-Formation
TASH
Teaching Exceptional Children
Texas Neuro Rehab Center
The Autism Recovery Foundation
The Center for Discovery
The Disability Resource
The Endorphin Corporation
The Hali Project
The Liberty Motor Co Inc.
The National Neurofibromatosis Foundation, Inc.
TherAdapt Products Inc.
Time2Read
Today's Caregiver
Trac About, Inc.
UCP
United Parents' Syndicate on Disabilities
Universal Motion
US Customs Service
US Department of Energy
US Department of Justice
Vail Products Inc.
Viewpoint Mobility
Vision for Life
Volkswagen of America
W.B.Saunders/Mosby/Churchill
Wal-Mart Stores, Inc.
Walt Disney World Company
Wheelchair Getaways Inc.

Exhibitors at press time

BEST COPY AVAILABLE

For complete details, visit our website at www.wcdexpo.com.
For a free conference brochure, call: (877) 923-3976 x832 or email: wcdinfo@wcdexpo.com

We are Stardust, We are Golden

Reflections on an international conference on practice and professionalism

by Marianne Taylor

In June 2002, direct support professionals (DSPs) and their advocates from around the world gathered in the college town of New Paltz, NY for three days of celebration and learning. Hosted by the Mid-Hudson Coalition for the Development of Direct Care Practice and the State University of New York at New Paltz, the conference was called Common Threads. Conference participants shared the excitement that comes from being part of something very special and contributed to the synergy that occurs when great people and creative ideas come together.

The conference had a theme song, also named "Common Threads." The title suggests that like a familiar flannel comforter, human services support needs no explanation across cultures; it is global in its purpose of serving humanity. Throughout the world it is a fabric that weaves together the threads of comfort, education, hope and healing that comprise the universal language of direct support.

As the parent of a child who is struggling to move beyond the obstacles of his disability to make friends and be successful in the world, it is impossible for me to imagine how he and our family could face this often-difficult journey without the assistance of competent supporters. At the conference I traded war stories with a dad whose early experi-

---

RESPITE-A CONSUMER'S PERSPECTIVE

Dani & Gene Feierstein

Respite: Time away from disabled family members, usually paid for by an agency other than the parents. The purpose is to give caregivers time away from some of their responsibilities and, it is hoped, reduce their stress level. While respite can be a great relief for a stressed-out parent, it is ultimately the parent's responsibility to make it work.

Respite services are generally not well publicized, so parents will have to seek them out. Contact your local mental health agency as a start. Once you have found a source, you will have to select a respite worker. Unless you are employing someone you already know well as a respite provider, talk with candidates before leaving your child in their care. Get references and check them, just as you would for a day care provider. Ask about the type of training and experience they have and where they got it. Is their CPR certification current? How recent is their first-aid training?

After you have talked to them all, ask yourself if you want to hire any of them. Did each one listen and ask pertinent questions? Did each one seem interested in working with your child? This is a job interview; don't be afraid to follow your instincts. If you decide to hire someone to care for your child, negotiate a mutually acceptable price for their services or research the set rate in your area.

Be very clear about what you expect from your respite worker. Is s/he allowed to bring children or anyone else along? Agree upon rules for the use of telephones and other household appliances. Some areas allow respite providers to transport clients in their own cars. If you are comfortable with this, make sure that the car is insured and in good shape. Decide who pays for the gas. Don't forget to leave a car seat or a booster seat if your child needs one.

You have a right to find your house the way you left it. This does not mean that the respite provider is also supposed to clean the house. I also appreciate it when telephone messages are written down.

Discipline is another issue that needs to be thoroughly discussed. Explain why and how you discipline your child and that you expect the respite provider to enforce the rules accordingly. No respite worker should physically punish a child.

Make it clear that calling in to see how things are going does not mean you don't trust the provider. When you return, expect to be told what happened in your absence.

BEST COPY AVAILABLE

ences in bringing up his beloved but hell-raising (his description) son were remarkably similar to mine; we laughed and wished each other well. Knowing fully that our futures and the futures of many others are highly dependent on qualified direct support staff, we were both at the conference to work for a better future for us, for our loved ones with disabilities and for direct support professionals.

DSPs touch deeply the lives of the people they support. The character of this touch is shaped when the raw materials of commitment, creativity and concern are cultivated to their greatest potential and effectiveness by a combination of theory, guided practice and an ethical framework. Conversely, we endanger and devalue those who rely on direct support and betray the spirit of human service work when we fail to invest in the preparation and recognition of DSPs.

That is, in its valuing of each person regardless of disability, vulnerability or life condition, direct support provides a profoundly transformative and radical response in a world that some would argue is moving toward the extremes of materialism and behavior devoid of social concern.

This was the situation in South Africa before Nelson Mandela was elected, explained keynote speaker Lesley DuToit, the former special advisor to the Minister of Welfare in the Mandela government. DuToit described the horrors of a national social service system that had institutionalized—warehoused—most at-risk children, neglecting them and providing no support. Mandela, DuToit and others reformed this system through a philosophy of the native American Lakhota tribe. Called the Circle of Courage, it promotes a focus on the characteristics of generosity, mastery, independence and belonging. DuToit described how workers helped transform the lives of children in this system by using these guiding principles and the strategy of focusing on one child at a time. What a remarkable opportunity to make a difference in the lives of South African youth!

continued on page 44

If it helps, create a checklist of things to discuss with the provider. When we went away for a weekend, I left written instructions about meal times, menus, snacks, bed and nap times. Because my son likes his routine, I wrote down things like his favorite blankets, stories and other little things. Remember: you know the routine that works for your child; your provider doesn't.

Your provider has a right to any information that has to do with caring for your child. Outline what your child likes and dislikes and explain how you deal with difficult situations. If your child understands, explain what is happening so that the respite worker does not have to deal with a surprised child when the parents leave.

Your respite worker has a right to expect things from you, too. I always give providers a binder containing all the information they might need. You must take the time to explain such things as the timing and dosage for medication and whether or not it should be taken with food. Let providers know if a reaction can be expected. Dietary requirements should also be described in detail.

Remember to leave a current medical release form with the respite worker. Some hospitals and doctor's offices will let you leave one on file with them. Leave doctors' names, addresses and phone numbers and all health insurance information, including the child's Social Security number. I also post emergency information on the refrigerator. If I am going away for the weekend, I leave menus, schedules, emergency contact information and money for food and bus fare.

A respite provider has the right to expect your home or apartment to be in acceptable condition, with a functioning telephone. Tell your provider if you have pets. Some people are afraid of animals or are allergic to them. If this is the case, secure the pets where the caregiver won't have to deal with them.

Let your neighbors, friends or someone you trust know when you are going away, when you will return, and who will be in the house taking care of the children. Leave telephone numbers of neighbors or friends as a precaution. This does not mean that they will check up on the respite provider, just that they will be aware that you are away. It is another way of making sure that everything is O.K.

It is sometimes hard to gauge children's reaction to respite. You need to ask them questions when you return. If your child is non-verbal, it might be more difficult. Ask for feedback from the respite worker too. Find out what worked for them - and what didn't.

Dani and Gene Feirstein have been consumers of respite services in both California and Virginia, where Dani also served as a respite provider. They have a 22-year-old son with a congenital genetic disorder.

BEST COPY AVAILABLE

THE CENTER FOR CHILDREN • HOSPITAL FOR JOINT DISEASES

Caring for children with
Cerebral Palsy
requires the help of many specialists.

Now you can find them all at
one special place.

The Center for Children is the one place you'll find all the care options you need, with just one concern in mind: your child. By bringing together the resources of the Hospital for Joint Diseases (HJD) and the Rusk Institute of Rehabilitation Medicine (RIRM) of NYU Hospitals Center, we can care for a variety of conditions in one convenient setting. For example, you'll find the widest possible range of treatments for children with cerebral palsy, with in-house specialties including pediatric physiatry, orthopaedics, speech therapy, neurology, neurosurgery, physical and occupational therapy. All in a gentle, kid-friendly environment where there are no white coats, but plenty of color, interaction, toys, games and stimulation. From newborns to 21-year-olds, The Center for Children treats them better. **Call us at 212-598-2330.**

The Center for Children
Hospital for Joint Diseases
301 East 17th Street • New York, NY 10003 • www.jointdiseases.com

For additional comprehensive pediatric services, contact:
NYU Children's Health
866-CHILD-NYU

MOUNT SINAI NYU
HEALTH

Circle #60 or visit www.eparent.com/adinfo

continued from page 43

At a session presented by the National Alliance for Direct Support Professionals (NADSP), a voluntary, national coalition that advocates for improving the conditions of direct support work in the United States, members invited workshop participants to describe the meaning that they find in their work. Many people at this session, and throughout the conference, described human service work as a gift of the spirit, noting how much they receive from the people they support and how great it feels to make a difference in someone's life. One woman told a story of the joy she felt when, after six months of teaching one man the use of a napkin at meals, he used a humorous and pointed non-verbal gesture while they shared a meal, showing that not only had he learned how to use a napkin but he thought that she should use hers.

As speaker Martin Brokenleg explained, in the Lakhota culture generosity becomes a springboard for healing and renewal; the act of giving away what is dearest is painful but liberating, permitting the giver to start over. Several people talked about human services work as an opportunity to live in the grace and generous spirit that is fundamental to the religions of the world: treating others as you would like to be treated. How many jobs provide this opportunity?

Harold Jacobs, a professor in the sociology department of SUNY-New Paltz, described it in this way: "Direct support demonstrates the humanized vision of a future that is not yet fully manifest." That is, in its valuing of each person regardless of disability, vulnerability or life condition, direct support provides a profoundly transformative and radical response in a world that some would argue is moving toward the extremes of materialism and behavior devoid of social concern. This does not mean, however, that DSPs must take a vow of poverty, earning less than a living wage. Jacobs went on to say that social justice demands a salary commensurate with the complexity and responsibilities of direct support.

In its working session linked to the conference, the NADSP continued efforts on a series of statements that will call for better working conditions for direct support professionals. Called the Moving Mountains NADSP Workforce Development Principles, they represent a call to human services systems, employers and organizations to align our actions with our rhetoric by shaping better workforce conditions for DSPs.

We also asked people to tell us what should be done to make human services a viable career choice. Their answers are the "common threads" that NADSP members hear from their peers across the country: recognition in all its forms, having a voice in decisions, having a professional image and the credentials to back it up and earning an income that is sufficient to maintain a family. These are the common threads that weave together our agenda for a stronger direct support workforce as we work to:

- Enhance the image of the role and the field of human service;
- Provide access to high-quality education and training;
- Change the system to assure a stable, competent workforce;
- Support the partnership of people with disabilities and support practitioners; and
- Promote the development of career paths.

We must find ways to jump-start the extensive transformations needed to create high-quality direct support over the long term. The Common Threads conference provided inspiration and a forum for these important discussions. EP

Marianne Taylor is the Senior Project Director at the Human Services Institute, an NADSP (National Alliance for Direct Support Professionals) co-chair and mother of a son with special needs.

Lifespan Respite Bill Introduced to Congress

On May 9, 2002 Senators Hillary Clinton of New York, Olympia Snowe of Maine, Barbara Mikulski of Maryland and John Breaux of Louisiana introduced The Lifespan Respite Bill, S2489, to Congress. If passed, the bill mandates the implementation of and funding for "coordinated systems of accessible, community-based care services for all caregivers of individuals regardless of the individual's age, race, ethnicity or special needs." These programs would be available to parents, family members, (including grandparents), foster parents and certain other adults who care for people with special needs. The bill calls for $90.5 million fy 2003, and increasing to $200 million fy 2007. These funds would be disbursed on a competitive grant basis to states and certain localities, depending on their likelihood of improving statewide respite care. At present, no federal programs exist to handle this type of care.

BEST COPY AVAILABLE

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Serving Adults having MR/DD

Visit us on the Web:
www.annandale.org

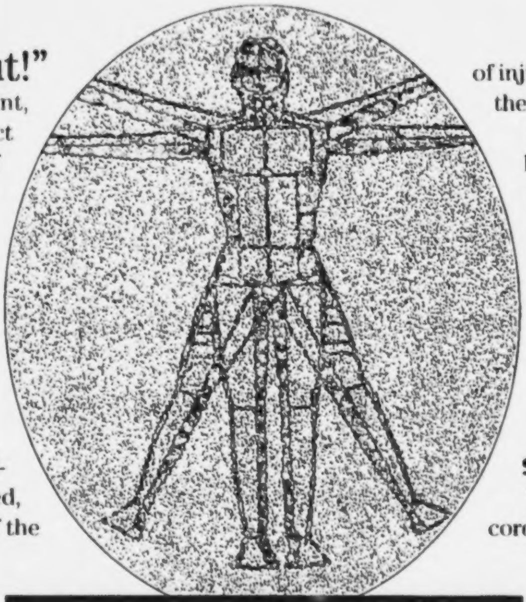
3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #19 or visit www.eparent.com/adinfo

LIFTING AND CARRYING CHILDREN WITH SPECIAL NEEDS:

Back Injury Prevention for Parents



By Carolyn O. Cantu, MS, OTR

"My back went out!" Sounds like a familiar complaint, especially from parents and direct support professionals (DSPs) of people with disabilities. The daily parenting tasks for exceptional children are a special challenge. A typical day involves bending, lifting and carrying the children, their orthotic devices, therapy equipment and wheelchairs. Transport occurs in and out of cars, vans and the house. There may be transfers from the wheelchair in and out of the tub, the bed, and the feeding chair, or on and off the toilet. Consequently, lower back pain and back injuries are a frequent occurrence, but there are prevention measures available.

The U.S. Department of Labor reported that in 1994, overexertion and handling of heavy objects led to 330,000 back injuries; the annual figure is now more than 370,000. More than 85 percent of adults—most between the ages of 35 and 55—have periods of intermittent or chronic low back pain. Labor reports also show that the longer a worker continues at a job requiring lifting, the higher the risk for back injury. Although specific statistics are unavailable, it is reasonable to extrapolate these numbers to the parents and DSPs of children with special needs. By nature of the role, parents of young children and children with disabilities fall into that high-risk category. You may have been or are presently among the parents suffering with back pain or injury. As long as you are lifting, carrying and transferring children, this information is for you.

Usually, the cause of back pain is an injury resulting from lifting a heavy object or executing an abrupt movement. Most typically, the offending action is lifting combined with a twisting motion. Recurrence is very common after the first episode because muscles have been weakened. This is significant for an employed parent, because the recurrence of injury results in additional time lost on the job.

Each year, Americans lose 93 million days of work to back injury or pain, at a cost of $11 billion. Direct medical expenses add another $20 million or so. That is a lot of time off the job, and at a high price. Chances are most of us do not have that many sick days—or discretionary income—to spare for one injury.

Spinal Anatomy Simplified

The back is made up of the spinal cord running through the center openings (foramen) of the vertebral bones, intervertebral discs, ligaments, nerves and muscles. The 33 vertebral bones are stacked up one upon the other and aligned into five sections, from the neck down: 7 cervical, 12 thoracic, 5 lumbar (the largest; they bear the most stress), 5 sacral and 4 coccyx. Of the 33 vertebrae, 24—ranging from the neck through the lower back—are movable. The bones in the sacrum and the coccyx are fused so they do not move. The vertebrae are arranged in an S curve; each is separated from the next by an intervertebral disc (cushion). Stability of the lower back depends on the integrity of the vertebral bones and intervertebral discs. Disorders and displacements of these discs are common causes of lower back pain. The muscles that surround these bones move the vertebral column. Interestingly enough, they are not the muscles that aid in keeping the body erect and stable. That work is done by the hip and thigh muscles, which are not solely responsible for posture and movement. Strong abdominal muscles are essential to maintaining a strong, stable back, enabling ease of trunk movement. The most common structures injured lie within the lower lumbar area. These include the 5 lumbar bones of the vertebral column, the discs between those bones and the muscles sup-

continued on page 48

All children should be seen. And heard.

BEST COPY AVAILABLE

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #63 or visit www.eparent.com/adinfo

continued from page 46

porting that section of vertebrae. Consequently, lower back injury and pain run along the lower portion of the back under the waist and between the hips.

Back Pain Triggers

Common causes of back pain include improper spinal alignment, improper posture in sitting and standing, and improper lifting and carrying. Consequently, when alignment, posture and movement techniques are neglected, injury or strain are likely to occur.

There are two classifications of back pain, acute and chronic. Acute attacks are experienced as sudden lower-back tension or stiffness, or as muscle spasms with sharp pain. Frequently, the pain runs across the upper portion of the buttocks and occasionally down the back of the leg. Quite often, the person is frozen in position and slides to the floor to lie down. This is very disturbing when caring for children, especially when a child is totally dependent on the parent's well-being. Chronic back pain is characterized by constant discomfort lasting three months or more. It is usually caused by repeated or unhealed injuries to the same area. Episodes of recurrent or intermittent pain occur over the years.

Proper lifting from a standing position involves keeping the child centered, as well as making contact with the palms of your hands.

Proper lifting from a kneeling position involves bending the knees, maintaining the natural curve of the back, and keeping the child close.

Common childcare situations that trigger improper lifting and carrying include lifting a child from the side (using a twist-and-lift pattern of movement), lifting and carrying on the hip, or lifting and twisting to put the child in a crib, enclosed play area, high chair or wheelchair. Other injuries occur while transferring large play or therapy equipment from one location to another, carrying two children at the same time, or carrying an infant or toddler while leaning to the side to hold an older child's hand.

Avoiding or Ameliorating Back Pain

By applying simple techniques to daily activities, parents and DSPs can reasonably expect to reduce back injury and pain.

PREPARATION: Simple preparation before every lift will ease the procedure.

- Stretch and flex all large muscles in back and limbs.
- Know the weight of the person. If the person weighs more than 30 pounds, get help or use a sliding or wheeled platform.
- Check the transport area, ie, the route between where the person is and where he is going. Check for obstacles and tripping hazards. Correct the pathway, if necessary.
- Observe stairs, ramps, curbs, inclines, walking space and blind corners.
- Check the area on which you intend to place the child. Make sure it is cleared, sturdy and at a comfortable level.

BODY MECHANICS: Body mechanics use the forces of gravity and inertia to advantage by determining the best possible positions to reduce stress or strain to the back. Practicing these mechanics might be an effort at first, but as they are put into daily practice they will become second nature.

- Maintain the natural S curve of the back. Do not straighten your back to an unnatural line.
- Bend the knees to use the large hip and knee joints and the strong leg muscles for lifting.

BEST COPY AVAILABLE

Keys to Prevention of Back Injury

- Maintain proper posture
- Keep natural back curve
- Use a wide base of support
- Maintain a low center of gravity
- Keep child close to the center of your body
- Do not twist while carrying a child
- When possible, slide instead of lift
- Use lifting equipment when necessary
- Consult with therapist about the best lifting principles for you and your child

- Tighten the stomach muscles, thus stabilizing the pelvis and spine.
- Maintain a wide base of support by standing with your feet under your shoulders. Balance is weakened if the feet are closer together or wider apart than shoulder width. When lifting a child from the front, your base of support is your two feet, separated, one slightly in front of the other. If your balance wavers, the back foot is ready to catch the sudden shift of weight and center of gravity.
- Keep the center of gravity low and within your base of support.

LIFTING AND CARRYING: Attend to the child. Do not allow yourself to become distracted.

- While lifting and carrying, keep the child close to your body and centered. If possible, have the child's legs straddle your waist. Carrying a child on one hip shifts your alignment to that side, putting a greater strain on your back.
- Lift only to waist level. Any overhead lifting puts a greater strain on the vertebrae.
- When lifting to carry toward another direction: Keep the child centered, place one foot in the direction of the lift, then move both feet in that direction.
- Move your entire body forward as a whole. Do not twist part of your body to place a child down. If you need to turn, turn by either pivoting or using small steps.
- While lifting, grasp the child firmly with the palms of your hands. If necessary, move the child slightly to one side to get a better grasp on his body. If lifting from the

continued on page 50

email mobility@freedomconcepts.com

freedom

what is your definition?

freedom has a different meaning for everyone. at freedom concepts we want to know your definition of freedom! we work with you, your doctor and your therapist toward a common goal, mobility. **talk to us, get our wheels turning and we will create a custom mobility solution just for you!** write us, email us, or call us today!

Featured photo rear steering assisted bicycle.

www.freedomconcepts.com

FREEDOM Concepts Inc.

1.800.661.9915

Circle #35 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

915

continued from page 49

floor, rest the weight of the child on your knee or thigh until you get your hands in a secure position.

- Lift in stages if necessary. If, for instance, you are transferring a heavy child or a child with low muscle tone from the floor to the changing table, lift from the floor to a platform near the table, then from the platform to the table.
- Always ask for help with a child that weighs 30 pounds or more. If you are using a two-person lift, have the adult with the heavier part of the child (usually hips and bottom) say the "1,2,3 Lift" commands.
- Make sure you are able to see over or around the child's head as you move from one location to another. This is especially important as you travel down stairs or up and down curbs. If the child slips while being carried, lower her gently to the floor while maintaining a natural back position. Do not rotate.
- If transferring someone from a wheelchair to another surface, move the wheelchair as close to the surface as possible. After removing the side arm, if at all possible use a sliding board instead of lifting. Ask your child's therapist about correct sliding transfer methods.
- Consider infant/toddler bath seats or hydraulic lifts for bathroom lifts and transfers. Consult with your child's therapist.

STOP…THINK…LIFT…TRANSFER

Back pain and injury while caring for children with special needs are preventable. These thoroughly tested methods can significantly reduce the risk of recurrent injury and pain. Parenting children is physically demanding. Those demands can be met by using techniques that keep backs healthy, strong and free of injury and pain; they are well worth attention and practice. EP

Carolyn Cantu is a pediatric occupational therapist and educator formerly with the Infant Parent Program Austin, TX. She is presently writing articles for publications focusing on the care of children with special needs and their caregivers.

BEST COPY AVAILABLE

The BEST strollers in the WORLD!
by Baby Jogger

Our Special Needs strollers are lightweight, easy to fold, and a joy to push...

www.babyjog

Circle #58 or visit www.eparent.com/adinfo

HMS Enables Active Learning

HMS School for Children with Cerebral Palsy serves children, ages 2-21, who have multiple disabilities resulting from cerebral palsy or traumatic brain injury. Skilled, compassionate staff and consultants provide individualized interdisciplinary programs that enable each child to flourish and learn.

Day & Residential Programs • Special Education
Physical & Occupational Therapies • Speech/Language Therapy
Music Therapy • Nursing & Nutrition Services • Medical Support
Therapeutic Recreation

State-of-the-Art Assistive Technology:
Augmentative/Alternative Communication
Computer Access
Environmental Control
Powered Mobility

For more information contact:
Diane L. Gallagher, Ph.D., Director
HMS School
For Children With Cerebral Palsy
– FOUNDED IN 1882 –
4400 Baltimore Ave., Philadelphia, PA 19104
215-222-2566 • Fax: 215-222-1889
www.hmsschool.org
E-Mail: admin@hmsschool.org

Member: NAPSEC • Pennsylvania's Alliance of Approved Private Schools

Circle #40 or visit www.eparent.com/adinfo

The Center for DISCOVERY

The Center for Discovery is certified by New York State through the State Education Department, the Department of Health and the Office of Mental Retardation and Developmental Disabilities (OMRDD); and by the Commission on Accreditation of Rehabilitation Facilities (carf).

Visit us at Booth #730 at The World Congress & Exposition on Disabilities in Orlando, Florida — October 3-5, 2002

Please read the four-part series, "Transitions: Informing, Empowering and Keeping Parents Involved," (June through September) currently appearing in Exceptional Parent Magazine.

Don't miss the special presentation, "Transitions: Informing, Empowering and Keeping Parents Involved," at the WCD (Oct. 4, at 2:00 p.m.) that will address the issues raised in the four-part EP series.

Be sure to attend the presentation at the WCD (Oct. 3, at 3-5 p.m.) highlighting the outcomes of The Center for Discovery 's International Summit, entitled "Disabilities: Sharing Visions for the Future" that was held at The Center this past June.

The Center for Discovery, a nationally-renowned prep school for children with significant disabilities (including multiple disabilities, medical frailties and some behavioral concerns) recently opened several new, small, universally-designed residences.

Located near Monticello, NY in the picturesque Catskill Mountains, just two hours northwest of New York City, The Center features a nature-based program that challenges children, and their families, to work with us to provide the finest educational, clinical, social and residential opportunities available anywhere.

We may just be the right program for your child.

Call our Admissions Office at (845) 794-1400, extension 1444 for information and/or to arrange a personal tour and see *discovery* in action.

Ask for our new video.

Box 840 / Harris, NY 12742
845-794-1400, extension 1444
email: admiss@sdtc.org

Visit our websites:
www.thecenterfordiscovery.org
www.discoveryifi.org

BEST COPY AVAILABLE

Circle #59 or visit www.eparent.com/adinfo

organizational **spotlight**

Brittaney Spanier of Allen, TX was a normally developing child until she started to be very sluggish and weak around the age of 3. A muscle biopsy diagnosed dermatomyositis. Now off her medication for 5 years, Brittaney, 10, remains almost symptom-free, except for her slow movement and likelihood of tiring. In addition to being a regular attendee at MDA summer camp, Brittaney is a cheerleader, roller skates and rides her bike.

Sarah Schwegel, 9, of Kirkwood, MO, is a jokemachine on wheels. Her spinal muscular atrophy necessitates the use of a power wheelchair and a full body jacket to counteract her scoliosis, but neither has affected her sense of humor or outgoing nature. Despite frequent hospitalization for pneumonia and severe scoliosis, her greatest strengths are communication, problem solving, reasoning, logic, being able to suggest adaptations, a positive attitude and a smile. Sarah was MDA's 2001 National Goodwill Ambassador.

BEST COPY AVAILABLE

The Muscular Dystrophy Association

"There are no incurable diseases, only diseases for which cures have not yet been found."

That was the hope and the philosophy of a group of adults and parents of children with muscular dystrophy who joined in 1950 to form the Muscular Dystrophy Association. That premise continues to guide MDA's course today.

MDA is a voluntary health agency working to defeat more than 40 neuromuscular diseases through worldwide research, services and professional and public health education. The Association supports more research on neuromuscular diseases than any other private-sector voluntary organization in the world while also offering the most comprehensive array of services of any voluntary U.S. health organization.

WHAT DOES THE MDA DO?

Because of its unique array of services, the MDA was the first nonprofit organization honored with the American Medical Association's Lifetime Achievement Award "for significant and lasting contributions to the health and welfare of humanity." Its programs include:

Worldwide Research. MDA awards about $25 million in research grants each year to scientists around the world seeking treatments and cures for

continued on page 54

Clay, Danny, Robin and Danielle Wagner live in Fort Lauderdale, Florida. Clay is autistic and has a seizure disorder.

"We're a PediaSure® Family."

"PediaSure helps us give Clay the nutrition he needs."

All kids need proper nutrition for growth and development. If your child is not getting enough of the right nutrition from regular food or has special feeding needs, ask your doctor about the complete, balanced nutrition of PediaSure. It's specially formulated to provide children with proper amounts of protein, fat, carbohydrate, vitamins and minerals. Available in your local supermarket, drug or discount store.

PediaSure
Pediatrician Recommended
Lactose Free

Available through WIC®*

*If your child has special dietary needs, check with your physician or local WIC clinic to see if your child is eligible to receive PediaSure through the WIC program. WIC is a registered trademark of the U.S. Dept. of Agriculture.

© 2001 Abbott Laboratories

Circle #53 or visit www.eparent.com/adinfo

organizational spotlight

When fraternal twins Aryn (left) and Erik (right) of Freeville, NY weren't walking by age 2, their mom Stephanie immediately suspected Duchenne muscular dystrophy. At age 5 the twins were put on the steroid prednisone. Aryn had heel cord and tendon release surgeries at age 8, and soon after began using a wheelchair. Erik walked until he was 10 years old, and now, at age 12, can take steps when wearing full-length braces. The boys also have learning disabilities, an occasional side effect of DMD. They enjoy swimming, therapeutic horseback riding, Nintendo, MDA summer camp and spending time with their two sisters and older brother, none of whom have muscular dystrophy.

Mattie J.T. Stepanek, 12, of Upper Marlboro, MD has mitochondrial myopathy, which affects his body's "autonomic" or "Automatic" functions. The condition causes generalized muscle weakness and also creates difficulty in regulating many body functions such as heart rate, digestion and breathing. When he was younger, Mattie could walk and even earned a black belt in karate, but now he uses a power wheelchair, a ventilator and extra oxygen as needed. Mattie still maintains a remarkable zest for life. A best-selling poet with a passion for peacemaking, Mattie is focused on making the most of his time. Mattie is the 2002 MDA National Goodwill Ambassador.

continued from page 52

the diseases in its program. MDA-sponsored researchers have made groundbreaking discoveries about the underlying genetic causes of virtually every genetic neuromuscular disease. In some cases, treatments which slow progression or ease symptoms have also been identified. MDA is currently funding research on several promising fronts, including the use of donated stem cells, gene therapy and drug therapy.

Nationwide Services Program. The Association provides a network of more than 230 hospital-affiliated medical clinics across the country, each staffed by doctors familiar with these rare conditions, as well as social workers, physical and respiratory therapists and other health professionals. Services are administered through local MDA offices and include free flu shots; assistance with the fitting, purchase and repair of wheelchairs and leg braces; loan closets of durable medical equipment; and parent and patient support groups.

Summer Camp Last year more than 4,000 children ages 6 to 21 spent a free week at camp - what many call "the best week of the year." Each camper is paired with a volunteer counselor who helps the child with practical matters and makes sure s/he joins in the fun.

Professional and Public Health Education MDA sponsors publications for affected families and for the general public about neuromuscular disorders, convenes international scientific meetings, and holds conferences of MDA clinic directors and their associates. An award-winning bimonthly magazine, *Quest*, and a series of pamphlets geared to those with new diagnoses help people stay on top of news and understand the effects of the disorders. Online support and information is available at http://www.mdausa.org, with materials in Spanish at http://www.mdaenespanol.org. Preschool disability awareness education is provided through MDA's Hop-a-Thon program in daycare centers and preschools.

BEST COPY AVAILABLE

WHAT IS A NEUROMUSCULAR DISEASE?

There are eight categories of neuromuscular diseases under the MDA umbrella. Among these are diseases that manifest at birth, those that present in early and late childhood and those that appear in adulthood. The underlying causes, levels of severity and rates of disease progression vary among the categories and the individual disorders.

All neuromuscular disorders cause weakness and wasting of voluntary skeletal muscles, but not all are life-threatening. Some forms are fatal in infancy, childhood or young adulthood, or within a few years of diagnosis, while others – although progressively debilitating – allow for a normal lifespan.

WHICH DISORDERS ARE COVERED BY MDA?

The following eight disease groups are the MDA's main focus:

Muscular Dystrophies Missing or defective proteins in the cells of voluntary muscles cause weakness and wasting over time. When the respiratory muscles are involved, death can occur in adolescence or young adulthood. Some forms spare respiratory muscle and target muscles in the trunk, arms, legs, neck and face instead. Muscular dystrophies include Duchenne, Becker, Emery-Dreifuss, limb-girdle, congenital and myotonic.

Motor Neuron Diseases Progressive degeneration of motor nerve cells in the spinal cord prevents the transmission of signals to the muscles. This group includes several childhood forms of spinal muscular atrophy (SMA).

Metabolic Diseases of Muscles These are caused by inherited chemical deficiencies of a specific enzyme, such as phosphorylase (McArdle's disease), acid maltase (Pompe's disease) or carnitine palmitoyl transferase.

Diseases of Peripheral Nerves These diseases include Friedreich's ataxia (characterized by shaky movements and unsteadiness) and Charcot-Marie-Tooth disease, which weakens the feet, lower legs, hands and forearms.

Inflammatory Myopathies The immune system is implicated in potentially debilitating disorders of

continued on page 56

YouCan HAVE THE BEST

Reliability.

Northstar, America's favorite in-floor ramp system, featuring a 10" lowered floor and 58" of headroom, provides an obstruction-free doorway. With standard One-Touch control, just a single touch of the remote silently deploys this reliable ramp.

Your Powerful Transportation Solution

VMI • 5202 S. 28th Pl. • Phoenix,AZ 85040

800-348-VANS

www.vantagemobility.com

vmi

Circle #66 or visit www.eparent.com/adinfo

continued from page 55

skeletal muscle, such as polymyositis and dermatomyositis. These diseases cause weakness of the pelvis, shoulders and limbs and may involve difficulty in swallowing.

Diseases of the Neuromuscular Junctions Conditions such as myasthenia gravis and congenital myasthenic syndrome (which is detectable at birth) cause problems with eye movement, facial expression, chewing, swallowing, respiration and, occasionally, arm and leg movement.

Myopathies Due to Endocrine Abnormalities Disorders of the thyroid can affect muscle function, sometimes causing weakness and wasting, while in other instances causing stiffness and painful cramps.

Other Myopathies This group of unrelated genetic muscle disorders (such as central core disease, nemaline myopathy, myotubular myopathy and mitochondrial myopathy) may cause diffuse weakness, some skeletal defomities and progressive muscle wasting, among other symptoms.

HOW DOES MDA FUND ITS PROGRAMS?

MDA has never received any federal funding. All funds come from private contributors, as well as national corporate and organizational sponsors.

Each year on Labor Day weekend, MDA presents the Jerry Lewis MDA Telethon—its trademark event. The broadcast boasts 21 hours of nonstop celebrity entertainment, information and recognition of donors, appealing to approximately 60 million viewers.

Each year, some 2 million volunteers participate in MDA's fund-raising, service and educational programs. This outpouring of support makes it possible for MDA to make good on its slogan: "Help for today, hope for tomorrow."

For more about MDA, look in your telephone book for the nearest MDA office; call (800) 572-1717; visit http://www.mdausa.org; or e-mail mda@mdausa.org. ■

Remember to tune into the 2002 Jerry Lewis MDA Telethon on Sept. 1-2 on the MDA "Love Network" station in your area.

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at
DISCOUNT PRICES!

As a service to our customers, we offer **FREE SAMPLES** of disposable youth briefs and pull ups.

GoodNites

Save up to 50%

Call **1 800 777 1111** 24Hrs
WOODBURY PRODUCTS, INC.
Order online at: **www.woodburyproducts.com**

Circle #64 or visit www.eparent.com/adinfo

MIDWEST MOBILITY & DESIGN INC.
ACCESSIBLE TRANSPORTATION

Drop Floor Minivans
Sport Pickups
4" x 6" Drop Floors
Raised Roofs & Doorways

- Rental Vans
- In Stock Units
- New & Used
- Ship Anywhere
- Financing
- Trade-ins

WWW.MIDWESTMOBILITY.COM

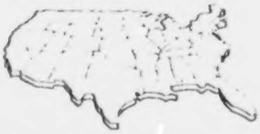
1-800-809-3738
NATIONWIDE
1-847-923-9892
CHICAGOLAND AREA

Since 1972
An All-Star Distributor of Braun Mobility Products

★★★★★
5 Star Dealership

Circle #48 or visit www.eparent.com/adinfo

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS



Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #44 or visit www.eparent.com/adinfo

ADAPTED SPORTS AND RECREATION

TECHNOLOGY AND EQUIPMENT

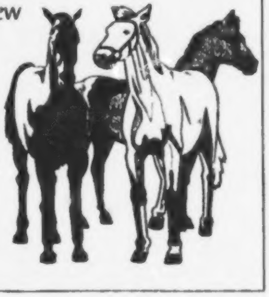
Adapted sports and recreation, a concept born in the early 1970's, is beginning to take a more prominent role in improving the quality of life for people with disabilities. The number of people with disabilities who engage in sports and other physical activities has increased dramatically in the past decade, due to the growing field of assistive sports and recreation equipment. Whether for competition, recreation or physical rehabilitation and development, the sports and recreation equipment market has developed many devices to encourage people with disabilities to participate in sporting events and programs.

Before programs like the Special Olympics, most children and adults with disabilities, health care professionals, and caregivers focused on basic life skills, needs and comforts. After years of realizing that that is not enough, the trend began to shift to organized physical activity as both a recreational release and a way to improve and maintain the health of people with disabilities. The results have been widespread.

EQUESTRIAN SPORTS

Equestrian sports have recently become very popular, as the technology has improved comfort for the rider. New equipment designs include:

- seats that have velcro straps and leg bands with seat covers
- saddle hand straps
- seat cushions and seat rolls to assist with balance and stability
- custom saddles
- mounting ramps and steps

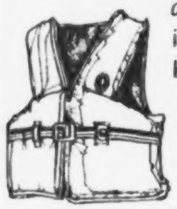


AQUATIC THERAPY PROGRAMS

Aquatic activities promote good muscle tone, lung capacity, flexibility and overall fitness without causing undue pressure on the joints and bones. Adapted equipment available for swimming includes:

- flotation vests
- swim fins
- water wings
- swim rings and head floats, all available to help keep the swimmer above water
- goggles for eye safety
- pool lifts and transfer tiers that help wheelchair users and non-ambulatory people transfer safely in and out of the pool

Specialty swimwear is also available that is lightweight, buoyant and insulated to protect against body heat loss with full-length side zippers or velcro fasteners, so that dressing is more manageable. There are specialty wheelchairs, including underwater and beach wheelchairs, parallel bars to aid in water ambulation and moveable swimming pool floors and platforms operated by hydraulic lifts.



BEST COPY AVAILABLE

MARTIAL ARTS, DANCE THERAPY AND AEROBICS

Martial arts, dance therapy and aerobics promote individualized fitness, wellness, cardiovascular endurance and muscular strength. Two therapeutic programs are chair aerobics and modified dance. Equipment needs are minimal, requiring only the appropriate amount of space, comfortable clothing that covers the body to keep muscles warm, suitable footwear and some music. It is very important to have a professional instructor who can help ensure the safety of the dancers.

An AbilityFirst karate class learns typical martial arts moves with the help of instructors and Arnold Schwartzeneggar.

BASKETBALL

A popular sport adapted for people with disabilities is wheelchair basketball. This is a team sport and therefore promotes good sportsmanship. This sport also improves overall health and strength as well as increases endurance and enhances fine motor skills. Some adapted equipment for this sport includes:

- *spoke protectors*
- *adjustable basketball hoop and posts*
- *specially-designed sport wheelchairs that are more easily maneuvered*

BEST COPY AVAILABLE

continued on page 60

925

Adaptivemall.com™

Shop On-line!

Tim's daughter Carrie.. a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.
Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #21 or visit www.eparent.com/adinfo

est. 1978

Consumer Care™
Rehab Specialties Division

Special Purpose Products for Special Persons and Those Who Assist Them

See Our New & Expanded Catalog on Adults & Children

Quality Crafted
in the USA

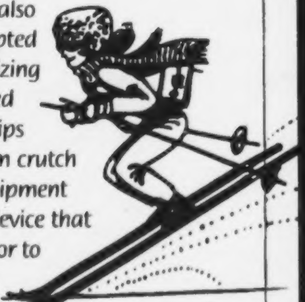
VISIT Our Easy To Use & Fast Access Web Site
www.consumercareinc.com

- See & Learn about Products & 3M Supplies
- Obtain Dealer Referrals
- Positioning Management Programs
- Lease/Rental Options
- Trial Use/Evaluations
- News & Valuable Tips

Consumer Care Products Inc. Rehab Speciality Division
1446 Pilgrim Road, Plymouth, WI 53073, U.S.A.
Tel: 920-893-4614 or FAX: 920-893-6195
E-Mail: ccpi@consumercareinc.com

Circle #27 or visit www.eparent.com/adinfo

WINTER SPORTS



Technology advancements have also increased participation in adapted winter sports, such as skiing utilizing ski stabilizers; ski handles designed to teach the user to keep ski tips together; and a flip ski, or forearm crutch with a ski attachment. Other equipment includes an all-terrain ski TD, a device that attaches the ski pole to the wrist, or to a prosthesis, and a four-piece boot shell device for skier's with lower extremity/ mobility disabilities.

continued from page 59

ABILITYFIRST

AbilityFirst is a non-profit organization located in Southern California that focuses much time and energy on providing adaptive sports and recreation equipment and programs for its clients. With its newest affiliate, MindBodySpirit, AbilityFirst has provided programs and services to people with physical and developmental disabilities for the past 76 years. AbilityFirst operates a network of 22 facilities throughout southern California, including community centers, adult vocational training centers, accessible housing complexes and accessible camps.

MindBodySpirit specializes in providing innovative martial arts training and adapted movement programs to children and adults with physical and developmental disabilities. AbilityFirst's MindBodySpirit adapted movement program includes activities such as:

- swimming
- basketball with AbilityFirst's wheelchair basketball team, the Los Angeles Stars (sponsored by the Los Angeles Lakers)
- drill team (adapted dance and aerobics team)
- ski school
- instruction in healthy living
- joint efforts with the Special Olympics and the Los Angeles Marathon

AbilityFirst community centers are equipped with accessible playgrounds, including equipment such as:

- safety swing chairs with straps
- wheelchair transfer ramps
- swing bridges for balance and gross motor development
- specially designed stairway play steps to assist with hand/foot coordination
- toss ball courts
- synthetic rubber mats under the playgrounds, to allow for easier wheelchair mobility.

AbilityFirst pools are equipped with bell bars for coordination and movement; aquatic noodles that provide flotation support and allow non-swimmers to improve their range of motion through leg kicks; hoyer lifts; and walking ramps so that clients can safely enter and exit the pools. AbilityFirst camps are completely accessible through equipment such as mounting ramps for equestrian sports and bowling ramps that allow bowling balls to be released from either a standing or sitting position.

The heart of AbilityFirst's philosophy is to encourage and seek to inspire individuals with developmental and physical disabilities to realize their full potential.

"The MindBodySpirit teaching philosophy is simple," states Stephanie Ivler, Chief Operating Officer and instructor for MindBodySpirit. "We strive to create an atmosphere conducive to excellence and then we step back and watch the students blossom. The adapted movement program is uniquely designed for our very special students to teach sports skills, to foster success in attaining learning objectives and to create opportunities for positive athletic experiences."

Adapted sports and recreation departments and programs have become an integral part of the offerings from adapted physical educators at universities such as Cal Poly in Pomona, CA, East Carolina University in Greenville, NC, and the Texas Women's University. Some city recreation departments including Pasedena, CA, Salt Lake City, UT, Carson City, NV. and Dayton, OH provide adapted recreation programs as part of the offerings at their community centers. All adapted sports and recreation departments have resources and adapted equipment available to ensure maximum benefits to the disabled recreation enthusiast. EP

For more information on adaptive sports and recreation equipment and programs, contact your local school or university's physical education departments and your local service agencies, or contact AbilityFirst's MindBodySpirit at (626) 396-1010. You may also visit AbilityFirst's website at www.abilityfirst.org.

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

HYPERBARIC OXYGENATION FOR THE COMATOSE CHILD

There is some hope for the comatose child suffering from severe brain injuries, cerebral palsy, or anoxic encephalopathy. Children with Glasgow Coma scales from 3-5 present tremendous financial and emotional burdens, since these little ones may live for many years. When considering care of tracheotomy, gastric tube for feeding, physical therapy, occupational therapy, speech therapy, nursing care, recurrent hospitalizations, medications, vans, and modifications to the home, expenditures may represent multi-million dollars.

Intensive hyperbaric oxygenation is no miracle, but it provides some hope. In certain instances the child is able to communicate verbally, by computer or word board. Eighty percent have the G-tube removed and seventy percent have the tracheotomies closed. Frequently, bowels become normal and nutrition is re-established. Routine monthly medications are reduced and hospitalizations are markedly decreased. Although few children will return fully to society, substantial improvements will give them a better quality of life in addition to a ninety percent reduction in overall costs.

For more information on hyperbaric oxygenation therapy and life planning, call the Ocean Hyperbaric Neurologic Center at (800) 552-0255.

Coming Soon!

Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child..

by R. A. Neubauer, M.D.

Dr. Neubauer's new book is a complete guide written for the professional as well as the caregiver of exceptional children. The book describes the latest information on hyperbaric oxygenation therapy including improved brain function as visualized through functional imaging. Clinical and scientific data along with references are included.

Call 1-800-552-0255 to order.

(800) 552-0255
Call for free video & information

For more information, visit:
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

Circle #49 or visit www.eparent.com/adinfo

BRADY | EPILEPSY
DAILY SEIZURES
MULTIPLE MEDICATIONS
FLUNKING SCHOOL
EXHAUSTION
ER VISITS EVERY MONTH
FALLING
LIVING IN A HELMET
A SEIZURE EVERY FEW MONTHS
ONE MEDICATION
ALL B'S
ENERGY
ONE ER VISIT LAST YEAR
FOOTBALL
HANGING OUT WITH THE GUYS

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

NCP
VNS
THERAPY™
VAGUS NERVE STIMULATION
Cyberonics

BEST COPY AVAILABLE

VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

Circle #68 or visit www.eparent.com/adinfo

929

EXECUTIVE SUMMARY[1]
SAFETY INFORMATION
FOR THE NCP® SYSTEM

INTENDED USE / INDICATIONS – UNITED STATES

The NCP System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures which are refractory to antiepileptic medications.

CONTRAINDICATIONS

- The NCP System cannot be used in patients after a bilateral or left cervical vagotomy.
- Do not use short-wave diathermy, microwave diathermy, or therapeutic ultrasound diathermy on patients implanted with the NCP System. Diagnostic ultrasound is not included in this contraindication.

WARNINGS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals. This is not intended to serve as a substitute for the complete NCP System Physician's Manual.

⚠ The **safety and efficacy** of the NCP System has not been established for uses not covered in the "Intended Use/ Indications" section of the manual.

⚠ The safety and efficacy of the NCP System treatment has not been established for stimulation of the **right vagus nerve** or of any other nerve, muscle, or tissue.

⚠ **Excessive stimulation** at a combination of high frequency (≥ 50 Hz) and an excess duty cycle (that is, one that occurs when ON time is greater than OFF time) has resulted in degenerative nerve damage in laboratory animals. An excess duty cycle can be produced by continuous or frequent magnet activation (> 8 hours), as determined by animal studies. Cyberonics recommends against stimulation at these combinations of ranges.

⚠ **Aspiration** may result from the increased swallowing difficulties reported by some patients during stimulation. Patients who have **pre-existing swallowing difficulties** are at greater risk for aspiration.

⚠ **Device malfunction** could cause painful stimulation or direct current stimulation. Either event could cause nerve damage and other associated problems. Patients should be instructed to use the magnet to stop stimulation if they suspect a malfunction, and then to contact their physician immediately for further evaluation. Prompt surgical intervention may be required if a malfunction occurs.

⚠ Susceptible patients with predisposed cardiac conduction systems (re-entry pathway) have not been studied as part of controlled clinical trials to establish the safety of NCP system treatment in these patients. Evaluation by a cardiologist is recommended if the family history, patient history, or electrocardiogram suggests an abnormal cardiac conduction pathway. Serum electrolytes, magnesium, and calcium should be documented before implantation. Post-implant electrocardiograms and Holter monitoring are recommended if clinically indicated.

⚠ **Sudden unexplained death in epilepsy (SUDEP):** Through August 1996, 10 sudden and unexplained deaths (definite, probable, and possible) were recorded among the 1,000 patients implanted and treated with the NCP device. During this period, these patients had accumulated 2,017 patient-years of exposure. Some of these deaths could represent seizure-related deaths in which the seizure was not observed, at night, for example. This number represents an incidence of 5.0 definite, probable, and possible SUDEP deaths per 1,000 patient-years. Although this rate exceeds that expected in a healthy (nonepileptic) population matched for age and sex, it is within the range of estimates for epilepsy patients not receiving vagus nerve stimulation, ranging from 1.3 SUDEP deaths for the general population of patients with epilepsy, to 3.5 (for definite and probable) for a recently studied antiepileptic drug (AED) clinical trial population similar to the NCP System clinical cohort, to 9.3 for patients with partial onset epilepsy.

⚠ **The NCP device is not curative:** Physicians should warn patients that the NCP System is not a cure for epilepsy and that since seizures may occur unexpectedly, patients should consult with a physician before engaging in un-supervised activities, such as driving, swimming, and bathing, and in strenuous sports that could harm them or others.

⚠ **Obstructive Sleep Apnea:** Patients with obstructive sleep apnea (OSA) may have increased apneic events during stimulation. Cyberonics recommends care when treating patients with preexisting OSA. Lowering stimulus frequency or prolonging OFF time may prevent exacerbation of OSA.

PRECAUTIONS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals.

⚠ **Laryngeal irritation** may result from stimulation. **Patients who smoke** may have an increased risk of laryngeal irritation.

⚠ **Dyspnea** may result from stimulation. **Patients with chronic obstructive pulmonary disease** may have an increased risk of dyspnea.

⚠ It is important to follow **recommended implantation procedures and intraoperative product testing** described in this manual. During the intraoperative Lead Test, rare incidents of bradycardia and/or asystole have occurred. As of October 1998, approximately 3,000 patients had been implanted with the NCP System. Four of these patients were reported to have experienced **bradycardia and/or asystole** during the intraoperative Lead Test. All four patients recovered without sequelae. One of the four patients was implanted with the NCP System. There were no postoperative or VNS-treatment-related cardiac adverse events later reported for that patient. No similar events were reported to have occurred during the clinical studies at the time of implantation or during treatment. The safety of this therapy has not been systematically established for patients experiencing bradycardia or asystole during NCP System implantation.

⚠ **Reversal of lead polarity has been associated with an increased chance of bradycardia** in animal studies. It is important to make sure that the Lead connector pins a correctly inserted (white marker to + connection) into the Pulse Generator header.

⚠ It is important to follow **infection control procedures**. Infections related to any implanted device are difficult to treat and may require that the device be explanted. Cyberonics recommends that the patient be given antibiotics preoperatively. The surgeon should ensu that all instruments, including the NCP Tunneling Tool, are sterile prior to the operation.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve** in the neck area inside the carotid sheath.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve below wher the superior and inferior cervical cardiac branches separate from the vagus nerve.**

⚠ A **neck brace** can be used by the patient for the first week to help ensure proper Bipolar Lead stabilization.

Environmental and Medical Therapy Hazards

⚠ Patients should exercise reasonable caution in avoiding devices that generate a **strong electric or magnetic field.** (For examples, see the "Other Environmental Hazards" sectio of the Physician's Manual.) If a Pulse Generator ceases operation while in the presence o electromagnetic interference (EMI), moving away from the source may allow it to return to its normal mode of operation.

⚠ NCP System operation **should always be checked** by performing device diagnostics afte any of the procedures mentioned in the Physician's Manual.

⚠ Because of where the Pulse Generator is implanted in the chest, **patients may need to b specially positioned in mammography equipment for clear imaging.** Otherwise, the device may be seen as a shadow on the mammogram. (Most routine diagnostic procedur such as fluoroscopy and x-radiography, are not expected to affect system operation.)

⚠ **Therapeutic radiation** may damage the Pulse Generator's circuitry, although no testing h been done to date and no definite information on radiation effects is available. Sources of such radiation include therapeutic x-rays, cobalt machines, and linear accelerators. The radiation effect is cumulative, with the total dosage determining the extent of damage. The effects of exposure to such radiation can range from a temporary disturbance to permaner damage, and may not be detectable immediately.

⚠ **External defibrillation** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for external defibrillation.

⚠ **Electrocautery surgery** may damage the Pulse Generator. Please refer to the Physician Manual for complete instructions for electrocautery surgery.

⚠ **Magnetic resonance imaging** (MRI) should not be performed with a magnetic resonance body coil in the transmit mode. The heat induced in the Bipolar Lead by an MRI body scan can cause injury.

Use caution when other MRI systems are used, since adverse events may occur because different magnetic field distributions

⚠ No scan in which the radiofrequency (RF) is transmitted by the body coil should be done o a patient who has the NCP System. Thus, protocols must not be used which utilize local coils that are RF-receive only, with RF-transmit performed by the body coil. Note that som RF head coils are receive only, and that most other local coils, such as knee and spinal coils, are also RF-receive only. **These coils must not be used in patients with the NCP System.**

⚠ **Therapeutic ultrasound.** Routine therapeutic ultrasound could damage the Pulse Generator and may be inadvertently concentrated by the device, causing harm to the patient.

⚠ **Extracorporeal shockwave lithotripsy** may damage the Pulse Generator. If therapeutic ultrasound therapy is required, avoid positioning the Pulse Generator part of the body in th water bath or in any other position that would expose it to ultrasound therapy. If that positioning cannot be avoided, program the Pulse Generator output to 0 mA for the treatment, and then after therapy, reprogram the Pulse Generator to the original parameters.

Diagnostic ultrasound is not expected to affect the NCP System.

⚠ The Pulse Generator may affect the operation of **other implanted devices,** such as card pacemakers and implantable defibrillators. Possible effects include sensing problems and inappropriate Pulse Generator responses. If the Pulse Generator patient requires concurrent implantable pacemaker and/or defibrillator therapy, careful programming of ea system is necessary to optimize the patient's benefit from each device.

ADVERSE EVENTS

Adverse events reported during clinical studies as statistically significant are listed in alphabetical order Ataxia (muscle movements or twitching, generally associated with stimulation); Dyspepsia (indigestion); Dyspnea (difficulty breathing, shortness of breath); Hypesthesia (impaired sense of touch); Increased coughing; Infection; Insomnia (inability to sleep); Laryngismus (throat, larnx spasms); Nausea; Pain; Paresthesia (prickling of the skin); Pharyngitis (inflammation of the pharn throat); Voice alteration (hoarseness);Vomiting.

Other potential adverse events possibly associated with surgery or stimulation include but are limited to the following:

Aspiration (fluid in the lungs); Blood clotting; Choking sensation; Damage to nerves or vasculature the surgical area, including the carotid artery and jugular vein; Device (Generator and/or Lead) migration or extrusion; Dizziness; Dysphagia (difficulty swallowing); Duodenal ulcer, gastric ulcer; Ear pain; Facial flushing; Facial paralysis, paresis; Foreign body reaction to implants, including possible tumor formation; Formation of fibrous tissue, pockets of fluid; Heart rate and rhythm changes; Hiccuping; Incision site pain; Irritability; Laryngeal irritation (sore, painful throat); Left hemidiaphragm paralysis; Left recurrent laryngeal nerve injury; Left vocal cord paralysis; Low-grad fever; Muscle pain; Neck pain; Nerve injury; Painful or irregular stimulation; Skin, tissue reaction; Stomach discomfort; Tinnitus (ringing in the ears); Tooth pain; Unusual scarring at the incision sit Urinary retention; Vagus nerve paralysis; Weight change; Worsening of asthma and bronchitis; Worsening of cardiac abnormalities, including heart rate and rhythm.

⚠ Patients who manipulate the Pulse Generator and Bipolar Lead through the skin may dama or disconnect the Bipolar Lead from the Pulse Generator and/or possibly cause damage to vagus nerve.

---

[1] The information contained in this Executive Summary for Physicians represents partial excerpts of important prescribing information taken from the *NCP Pulse Generator Physician's Manual*. The information is not intended to serve as a substitute for a complete and through understanding of the material presented in all of the Physician Manuals for the NCP System and its component parts nor does this information represent full disclosure of all pertinent information concerning the use of this product, potential safety complications, or efficacy outcomes.

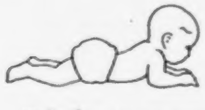
Advertisement

Is Your Baby Okay?

Watch for these signs that may indicate physical delays*

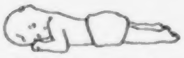
BY 3 MONTHS*

Normal Development

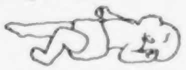


☐ Pushes up on arms
☐ Holds head up

Signs to Watch for



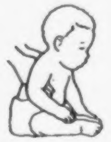
☐ Difficulty lifting head
☐ Stiff legs



☐ Pushes back with head
☐ Constantly fisted hand and stiff leg on one side

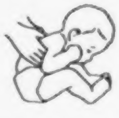
BY 6 MONTHS*

Normal Development

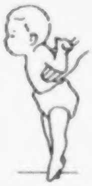


☐ Sits with support
☐ Holds head up
☐ Straight back

Signs to Watch for



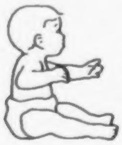
☐ Unable to lift head
☐ Rounded back
☐ Stiff arms



☐ Arms held back
☐ Stiff, crossed legs

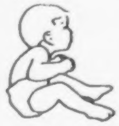
BY 9 MONTHS*

Normal Development

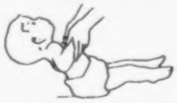


☐ Sits without support
☐ Arms free to reach and grasp

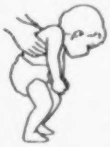
Signs to Watch for



☐ Rounded back
☐ Poor use of arms



☐ Difficult to get arms forward
☐ Arches back, stiff legs



☐ Poor head control
☐ Poor ability to lift head and back
☐ Will not take weight on legs

Watch for these signs of speech and hearing delays*

3 MONTHS*

☐ Does not quiet in response to sound or voice
☐ Does not cry differently depending on purpose
☐ Does not coo or vocalize other than crying

6 MONTHS*

☐ Does not smile in response to speech
☐ Does not begin to use consonant sounds in babbling

9 MONTHS*

☐ Does not smile or laugh while looking at you
☐ Does not turn to sounds or reach for objects
☐ Does not use voice to get help and attention

*90% of babies do these movements by the ages indicated. Remember to correct your child's age for prematurity.

Early detection is the best prevention!

Mark a check (✓) by any of these signs that you see in your baby. Or, write your concerns in a notebook to share with your child's doctor. It is important to keep track of your child's development so they get the best start in life.

Pathways Awareness Foundation

For more information contact us at 1-800-955-2445, or visit our web site at www.pathwaysawareness.org

Circle #51 or visit www.eparent.com/adinfo

THE JUNGLE OF UNOLAND:

A Fable for Our Time

Explaining the war on terrorism to young children

by Vidya Bhushan Gupta, MD

Once upon a time, in the jungle of Unoland, there lived a family of lions: Papa Lion, Mama Lion and two cubs, Manny and Maria. They had a nice den with a personal corner for each cub, and a backyard with flowers and shrubs. In the backyard they had a patio, where they could meet with the other animals of the jungle.

During the day, Papa and Mama Lion worked in the jungle collecting food for the cubs, and things for their den. Mama and Papa lion did not fight with other animals. All the animals respected them because they never bullied anyone. Once they even put Manny in time-out for pushing Matthew the colt during a race. Any animal that had a problem came to the Lions for help and advice.

Every month the lions threw a party to which they invited all the animals of Unoland and friends from neighboring jungles. Once they invited Sammy the bear from the jungle of Rubyland to their party. Sammy the bear did not bring Mrs. Bear and their cubs with him. He believed that only Papa Bear should go to meet other animals, while Mrs. Bear should take care of the cubs and cook and clean. He believed that parties could spoil cubs, who should learn to hunt and catch their prey. He did not like to give parties. He bullied other animals to do things for him.

Sammy did not like what he saw at the Lions' party. He did not like Mama and Papa lion dancing together. He was especially mad at Muny the bear, who was dancing with Ronnie the rabbit and Chunky the Squirrel.

"Isn't Muny ashamed of dancing with little animals?" Sammy thought. "How could a bear that is so big and so strong dance with squirrels and rabbits?"

Sammy was jealous, too. "There is so much food and grass and so many trees and shrubs in Unoland, while Rubyland is so poor," he thought.

When the party was over, Sammy said good-bye to Papa Lion and went back to Rubyland thinking how much he disliked Unoland. He was mad at Papa Lion for giving too much freedom to the weaker animals. He wondered how he could teach Papa Lion, and the animals of Unoland, a lesson.

Sammy called a meeting of all the male bears of the world including Muny and...

Calling all artists!

EP wants pictures of the characters in this story for possible publication in an upcoming issue. Read the rest of the tale at http:/www.eparent.com and send in your child's illustrations!

Dr. Gupta is Director of the Dept of Developmental Pediatrics at Metropolitan Hospital in New York City. Dr Gupta uses the fable to explain to young children about the war on terrorism, and to help them to differentiate between good people and bad ones. The story can also help young children distinguish between good and necessary fighting, such as the war on terrorism, or bad fighting, in school or on the street.

BEST COPY AVAILABLE

ALLERGAN

Allergan, Inc., with headquarters in Irvine, California, is a technology-driven, global health care company that develops and commercializes specialty pharmaceutical products for the eye care, movement disorder, and dermatological markets as well as ophthalmic surgical devices and contact lens care solutions. In over 100 countries worldwide, **Allergan** markets products that deliver value to its customers, satisfy unmet medical needs and improve patients' lives.

Founded in 1948, **Allergan** has approximately 6,200 employees worldwide with 2000 sales of nearly $1.6 billion. **Allergan** is a pioneer in specialty pharmaceutical research, with a strong pipeline of products and technologies related to specific disease areas such as glaucoma, retinal disease, cataracts, dry eye, pain, movement disorders, and retinoid technology platforms with applications in psoriasis, acne, photodamage, metabolic disease, and various types of cancer. The Company has demonstrated its commitment to the Research and Development function by increasing its headcount nearly 30% during the last three years.

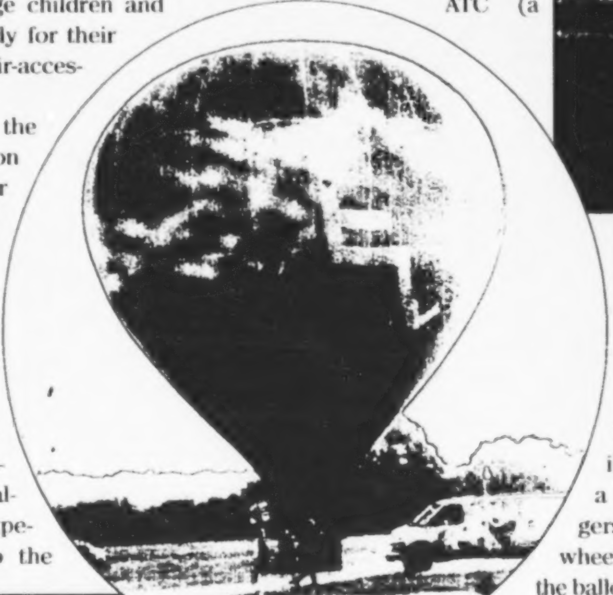
Circle #67 or visit www.eparent.com/adinfo

SERENA'S SONG

by Carolyn Cantu

As the early morning sun rose slowly over the skyline, a hot air balloon called Serena's Song lifted into the air over Zilker Park in Austin, Texas. On this clear, cool May morning, wheelchairs were lined up in three rows. School-age children and elderly alike waited expectantly for their turns to ride the first wheelchair-accessible hot air balloon.

After a dramatic burst of the blowtorch beneath, the balloon rose about 100 feet into the air and squeals could be heard from inside the adapted basket. Tethers attached to trucks and held by crew members controlled its rise. Gary Waldman, father of the girl for whom Serena's Song is named, controlled a tether from the ground while his partner, Phil Gray, piloted the balloon. Their confidence and experience were unmistakable to the group of would-be travelers and their caregivers.



Serena is a young woman with severe cerebral palsy. Seventeen years ago, Mr. Waldman took his then two-year-old daughter on a hot air balloon ride. Prior to this adventure, Serena had been unable to express recognizable emotion. Her father recalls that as the balloon took off, she squealed with delight and gave a shrill cry of happiness. Mr. Waldman's own thrill at hearing his daughter express such joy inspired him to attempt to provide others with this unusual experience. He hoped that the excitement of being lifted so high off the ground might stimulate other non-communicative children and adults to express emotion. Serena's Song is the balloon that has made this possible.

Approved by the Federal Aviation Administration (FAA) and sponsored by ATC (a transit operations service provider specializing in transportation for riders with disabilities), the balloon is built to carry a 250-pound person in a 250-pound wheelchair. The basket is fitted with a special 48-inch door, wheelchair braces and a "window" that enables passengers to view the scenery from wheelchair level. Unique in its design, the balloon itself is emblazoned with the international handicapped logo, wearing a red heart, on a bright blue background.

Serena's Song travels all over the United States, giving the gift of flight to people who ordinarily view their environment from the height of their wheelchairs. Corporate sponsorship from ATC allows Serena's Song to provide these exciting rides to a large population throughout the country. By helping to replicate Serena's experience for others, Mr. Waldman has provided more than 10,000 people the joy and exhilaration that his daughter experienced years ago.

One message on the Serena's Song web site message board reads "God Bless You, Gary," a sentiment shared by many who have experienced or supported this adventure… including this writer!

For more information about Serena's Song, including a tour schedule, visit http://www.serenassong.com. EP

BEST COPY AVAILABLE

Life threw Stephen a curve ball . . .

but that didn't keep him on the bench.

Key Statistics

Name: Stephen

Age: 11

Diagnosis: Cystic Fibrosis (CF), an illness that fills lungs with thick mucus and makes breathing difficult.

Favorite Positions: Shortstop
Pitcher

Throws/Bats: RH/RH

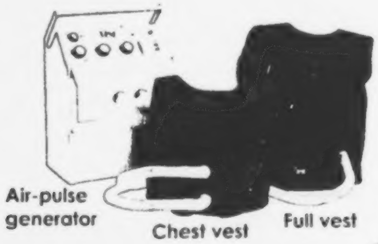
Favorite Player: Nomar Garciaparra

> **"Using The Vest system helps me stay at the top of my game."**
>
> ***Stephen, The Vest system user since 1998***

Many people with respiratory complications, like Stephen, rely on The Vest™ airway clearance system for comfortable, effective airway clearance therapy.

More than **3,000** physicians have prescribed The Vest system for more than **20,000** patients with respiratory complications associated with cerebral palsy, muscular dystrophy, cystic fibrosis and over **200** other diseases and conditions.

For more information about The Vest system, call us at **800-426-4224** or visit **www.thevest.com**.



The **Vest**™
Airway Clearance System

So everyone can breathe a little easier®

www.thevest.com

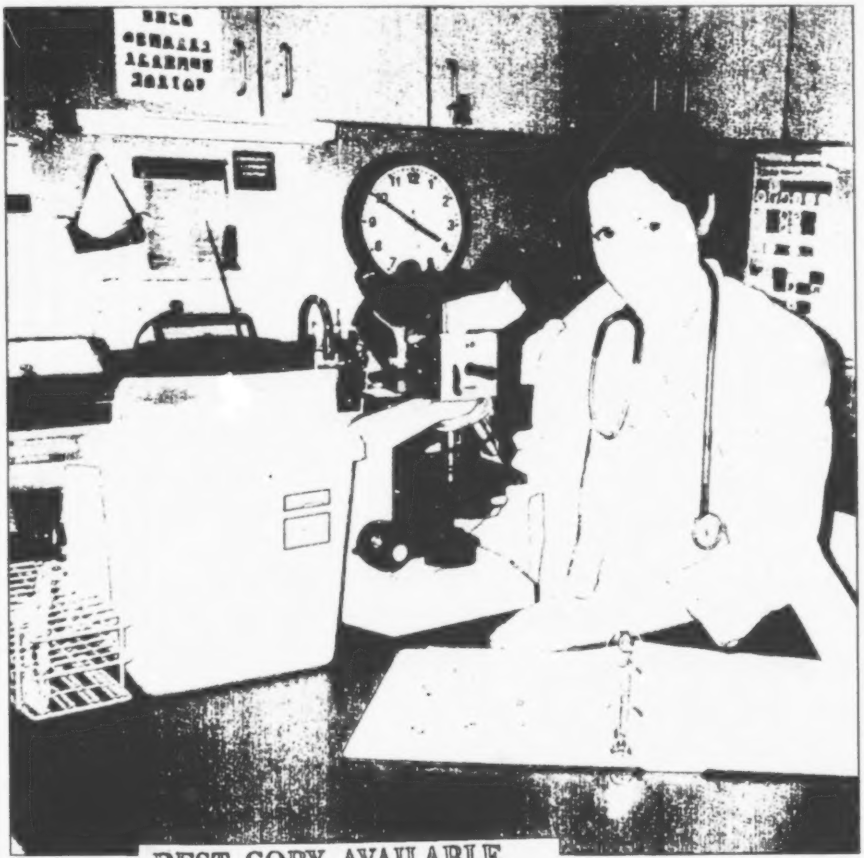
The Vest™ and "So everyone can breathe a little easier" are trademarks or registered trademarks of Advanced Respiratory. © 2002 Advanced Respiratory 501139 AA 06/02

Circle #18 or visit www.eparent.com/adinfo

A Physician's Question

by Galina Psakhis, M.D.

It is Tuesday morning (my clinic day) and as usual, I am chatting with my nurse and looking at my busy schedule. I notice that Nathan C. is coming today for a physical. I smile and ask my nurse to let me know as soon as he arrives. I like Nathan's family, particularly his very devoted mother. Nathan has autism and mental retardation. I met his family several months ago when he had a problem with school placement because of his aggressive behavior and incontinence. Since then I have thought seriously about patient advocacy and tried to think in terms of how a parent or caregiver would think about the challenges of caring for a patient with a disability or chronic health care condition. I took it upon myself to find out what resources are available and to whom to refer parents for quality information. These kinds of things are not skill sets we learn in medical school or when we do specific rotations, yet they are critical to my profession as a physician.



BEST COPY AVAILABLE

Let me introduce myself. My name is Galina Psakhis, and I am a second year resident at ETSU Family Practice Residency Program in Johnson City, Tennessee. I am a foreign physician who emigrated to the US from Russia eight years ago. I was an experienced practicing pediatrician in my country, and so I felt quite confident when I started my residency until one night while I was on call at the hospital.

On this occasion, I had to evaluate a mentally retarded patient with severe abdominal pain. I will never forget my feelings: hopelessness and a desire to leave the room and call my senior resident for help. I have to admit that I was incompetent to communicate with the patient. Even to examine him was a big challenge. It seemed we both were frightened of each other, although I had no reason to be scared. My confession about this struggle on the morning report did not bring the comfort I had hoped for. I learned that most of the residents have had similar experiences. My problem was not a language barrier but a lack of confidence and experience working with mentally challenged patients.

As I reflect on my past, I do not recall treating any mentally retarded patients in my 12-year medical career. In Russia, mentally retarded patients do not live long, and if they do they live in institutions. The philosophy is that if you do not see it, you do not have a problem. Here, in America, many types of information and services as well as advanced medicine are available in most communities. Social and

Dr. Galina Psakhis with a patient in Johnson City, TN.

family support systems provide an opportunity for many disabled people to live a normal life and be an important part of society. Americans tend to view people with special needs not as problems to be confronted but as people to be respected.

Modern medicine, science and technology have provided great help and opportunities for people with special needs so as to afford them the chance to make a positive contribution to our society. However, there is still a great need for improvement, especially in the educational arena. As a practicing physician, I am struck by how little we know about people with mental retardation: how they live, their daily needs, and, most important, how to find the right way to support and communicate with them and their families.

It was the last month of my internship when I was on my rotation at the Morton J. Kent Habilitation Center at Orange Grove in Chattanooga, Tennessee, a center for people with special needs, when I discovered Exceptional Parent magazine. I found myself reading it cover to cover. The

continued on page 72

BEST COPY AVAILABLE

THE MELMARK SCHOOL

2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Our approved private day and boarding school serves children ages 5-21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Acquired Brain Injuries
- Cerebral Palsy
- Mental Retardation
- Neurological Disorders

Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

We Offer Your Child:

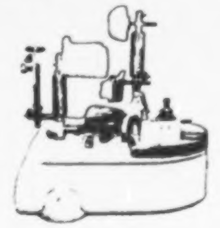
- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK Ext. 636 or email admissions@melmark.org

Circle #46 or visit www.eparent.com/ad info

Early Childhood Mobility
Mini Go-Bot's

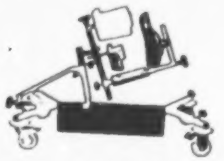
Century Stander



Stanford Standard

Note: Standing frames work with either Go-Bot

Yellow Go-Bot



GB-I Gait Trainer
(can be customized)

Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com

Circle #42 or visit www.eparent.com/ad info

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #57 or visit www.eparent.com/ad info

Resident's Letter

continued from page 71

patient stories were uplifting and when I looked inside to review the editorial advisory board, I instantly recognized some of the leaders in medical science, technology and education. I found myself reading some more. EP magazine is a great resource of information and support for the special needs community as well as a valuable source of medical information. I consider it one of the best sources for physicians, nurses, parents and caregivers.

Recently, I also learned about educational projects in some residency programs involving parents of handicapped patients who work as teachers for medical professionals. The unique advantage of these projects is direct and personal contact between residents, parents and patients in their homes that helps physicians get a more realistic picture of what it is like to have a disabled child. Despite the success and importance of the parent teaching projects, however, they are not universal, but limited to several well-respected university residency programs.

Development of core-curriculum guidelines for all primary care oriented residency programs would be a real solution and a great benefit to all parents and physicians. In addition, I feel that using EP publications for medical education as a supplemental resource of information about disability is imperative to help medical students and residents gain more exposure to this field.

The reality is that many residents will start their practices after graduation and eventually have patients with mental retardation or other forms of disability. Do we have enough contact and practice working with handicapped patients and their families during our medical training? Are we not obligated to do this as physicians? After all, these patients need our care and expertise just as much as those whose disease states we can cure with medication or surgery. The fact that they may have a lifelong condition only exacerbates the need for more training and experience in this field.

I started my letter to EP in order to invite residents, physicians and nurses to share their experiences with chronically handicapped patients and their families and to discuss different opinions in order to help us build better patient-doctor partnerships. I want to invite parents and caregivers to share with us your experiences and what would you like to see change in your primary care physician relationship. Ironically, the information gap exists on both sides. That is why communication and teaching are crucial and beneficial for all of us.

Sincerely,
Galina Psakhis, MD EP

Mentoring on the Internet

by Sheryl Burgstahler, PhD

Most of us can think of people in our lives, more experienced than we, who taught us something new, offered advice, presented a challenge, initiated friendship or simply expressed an interest in our development as a person. They helped us negotiate an uphill path or find an entirely new path to a goal in our academic, career or personal lives. They showed us a world larger than our neighborhood. They pointed out talents we hadn't noticed in ourselves and stimulated ideas about what we might be able to accomplish. They nudged us when we needed a nudge.

The Benefits of Mentoring

Each participant benefits from communication with several mentors. As participants move from high school to college and careers they too become mentors, sharing their experiences with younger participants. Mentors offer protégés:

INFORMATION: Mentors share their knowledge and experiences with protégés, often helping them realize they have more choices than they thought.

CONTACTS: Mentors introduce their protégés to valuable academic, career and personal contacts.

CHALLENGES: Mentors stimulate

continued on page 74

Mentoring: How DO-IT Does It

Most of my time at the University of Washington over the past ten years has been spent establishing, securing funds for and directing project DO-IT. DO-IT stands for Disabilities, Opportunities, Internetworking and Technology. DO-IT's goal is to increase the academic and career success of individuals with disabilities. To date, we have focused most of our efforts on those challenging teen years, helping college-capable young people successfully transition to college and on to employment. For every challenge we undertake DO-IT asks, "What role can technology play in solving this problem?"

Introducing protégés to mentors with similar disabilities is a strength of the DO-IT program. Most DO-IT mentors are college students, postsecondary faculty and other professionals who have disabilities. Mentors are selected after submitting an application form and undergoing a review process, including reference checks. Protégés are participants in the DO-IT Scholars, Pals or Campers programs who are making plans for post-secondary education and employment. They all have disabilities (including visual, hearing, mobility and health impairments) as well as specific learning disabilities.

Most mentoring in DO-IT takes place on the Internet. Electronic communication eliminates the challenges imposed by time, distance and disability that are characteristic of in-person mentoring. For example, participants who have speech impairments or are deaf do not need special assistance to communicate via electronic mail. Those who cannot use the standard keyboard because of mobility impairments use adaptive technology to operate their computer systems.

DO-IT also facilitates communication in small groups through the use of electronic discussion lists. For example, one group includes both mentors and protégés who are blind. They discuss common interests and concerns such as independent living, speech and Braille output systems for computers and options for displaying mathematical expressions and images.

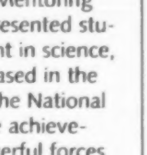
DO-IT's mentoring program has received national recognition with The Presidential Award for Excellence in Mentoring "for embodying excellence in mentoring underrepresented students and encouraging their significant achievement in science, mathematics, and engineering." It was also showcased in the President's Summit on Volunteerism and received the National Information Infrastructure Award "for those whose achievements demonstrate what is possible when the powerful forces of human creativity and technologies are combined."

Joining the DO-IT Mentoring Community

The DO-IT Scholars program, which includes multiple on-campus summer study programs and year-round mentoring, is funded by Washington state and is open to Washington residents. However, private foundations and corporate sponsors from other states can propose funding scholars from other states.

The DO-IT Pals electronic community is open to all teens with disabilities who are interested in pursuing college and have access to electronic mail. They communicate with DO-IT mentors, receive useful college and career information from DO-IT staff and make friends. For your teen to join DO-IT Pals, send electronic mail to doit@u.washington.edu and request a DO-IT Pals application.

Also visit http://www.washington.edu/doit/Programs/ for more information about these DO-IT programs.



Dr. Sheryl Burgstahler is the director of the DO-IT (Disabilities, Opportunities, Internetworking, and Technology) program. DO-IT is funded by the US Deptartment of Education, the state of Washington and many other organizations. DO-IT serves to empower young people with disabilities as they transition to college and careers through the use of computers, assistive technology and the Internet. "Tech Talk" is designed to address practical ways of integrating technology into educational, work and home environments. Dr. Burgstahler will also answer readers' questions through this column. Please send correspondence to: Dr. Burgstahler, University of Washington, Box 354842 Seattle, WA 98195; fax: (206) 221-4171; e-mail:sherylb@u.washington.edu.

continued from page 73

curiosity and build confidence by offering new ideas and opportunities that introduce protégés to advocating for themselves.

SUPPORT: Mentors encourage growth and achievement by providing an open and supportive environment.

DIRECTION: Mentors help protégés discover their talents and interests and devise strategies to attain their goals. One mentor explains, "I try to tell kids to listen to their hearts and think about what they really want to do… and go for it."

ROLE MODELS: Mentors accomplish many of these goals by letting their protégés know who they are. As one protégé shares, "I'm less shy now that I know there are more people out there that are just like me."

Mentors benefit from the mentoring experience as well. Protégés offer mentors:

CHALLENGES: Mentors develop their own personal styles for sharing their skills and knowledge via electronic communication.

NEW IDEAS: Mentors join an engaging community of talented students and professionals with a wide range of interests, abilities, and disabilities who are eager to share their own strategies for problem-solving and success.

FUN: Mentors share in the lives of motivated young people. Listening to them, hearing about their dreams and helping them along the road to success are just some of the fun activities!

Evidence of Impact

DO-IT has been studying the nature and value of electronic mentoring since 1993. Findings suggest that electronic mail can be used to initiate and sustain both peer-to-peer and

Learning by Association! *The Art of the Alphabet!*

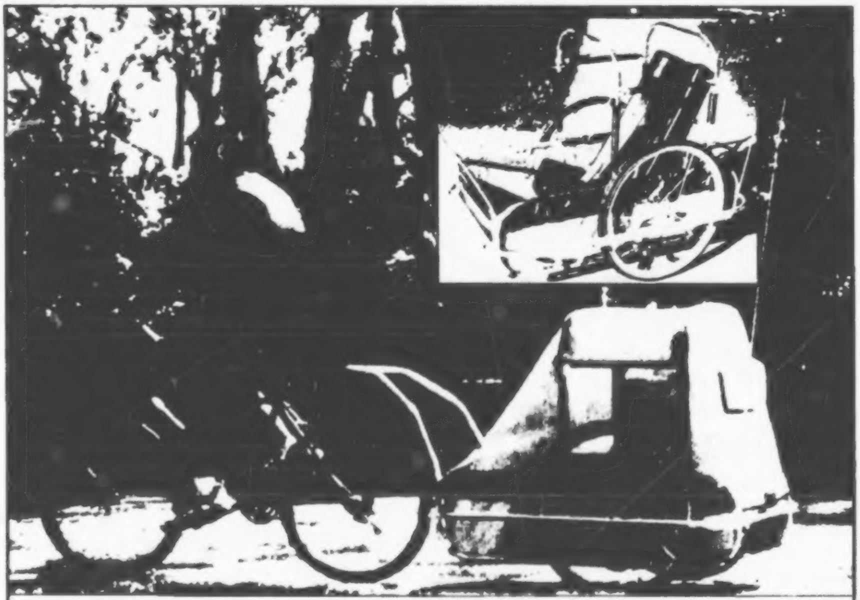
Alphabet Animals
The Bears
The Bunnies

Alphabet Animals $19.95 *(26"x20")*
Laminate Any Poster + $3.95 ea.
100% SATISFACTION GUARANTEED!
Bears or Bunnies
$9.95 ea. *(22"x18")*

Kid's #1®
Help your child know the alphabet before kindergarten!
Learning by Association
Copyright 2002 • All Rights Reserved
Kid's # 1, Inc. Minneapolis, Minnesota

Receive **FREE** ***Bears*** or ***Bunnies*** poster *with* purchase of ***each Alphabet*** poster!
When purchasing ***any two*** or more posters, *receive* **$1.00 DISCOUNT** each poster!
Order 24 hours a day/7 days a week
1-888-844-5200 or www.kids-1.com
VISA • MASTERCARD • AMEX • DISCOVER
Add $7.95 s&h • Minnesota residents add sales tax
INQUIRE FOR VOLUME DISCOUNTS OR WHOLESALE SC AGN005

Circle #43 or visit www.eparent.com/adinfo



Enjoy the out-of-doors together with a
CycleTote® Bicycle Trailer
Running Stroller
1-800-747-2407 www.cycletote.com
Satisfaction Guarantee/Lifetime Warranty

visit www.eparent.com/adinfo

mentor-to-protégé relationships while alleviating barriers to traditional communications such as time and schedule limitations, physical distances and disabilities of participants. Both young people and mentors report positive experiences in using the Internet as a communication tool. The Internet gives young people support from peers and adults who are otherwise difficult to reach, connects them to a rich collection of resources and provides opportunities to learn and contribute. Many also report that people treat them equally because they are not immediately aware of their disabilities, an added value.

Joining a Mentoring Group

Many discussion lists, chat rooms and bulletin boards invite people with a common interest to join and share their experiences and ideas; some even offer mentoring relationships. But how do you know if one of these communities is appropriate and safe for your child? As with any other activity in which you seek to involve your children, find out about the organization sponsoring and supervising the activity. Most chat rooms, discussion lists and bulletin boards are not monitored or supervised. If you find a mentoring community that seems appropriate for your child, ask about how mentors are chosen and trained or guided. Also, ask what guidelines are given to the protégés.

Most important, before you allow your child to communicate with anyone on the Internet, talk with them. Set the rules for safe communication. Try keeping your Internet-connected computer in a busy place in the house and regularly monitor your child's use of the Internet. Child safety is an important consideration whenever children are using the Internet, a topic I will cover in next month's issue of EP.

Guidelines for Mentors and Protégés

To ease mentors into their new positions, the following are a few suggestions for new mentors:

- Get to know the protégés. What are their personal interests? Academic interests? Career interests?
- Introduce yourself to the group. Share your personal interests, hobbies, academic interests and career path.
- Explore interests with protégés by asking questions, promoting discussion and pointing to resources.
- Encourage participation in activities and try to attend activities when possible. Mentor-protégé relationships are strengthened through face-to-face contact.

Remember that developing meaningful relationships takes time. Give yourself and your protégés time to get to know one another.

Protégés should also remember that mentors are valuable resources to them. Relationships developed with mentors become channels for the passage of information, advice, opportunities, challenges and support with the ultimate goals of facilitating achievement and having fun. To get to know mentors and develop this relationship they are encouraged to:

- Introduce themselves and share their personal, academic and career interests and plans.
- Ask mentors about their hobbies, interests and experiences in academics and careers.
- Seek mentors' advice about college preparation, entrance and success. Ask about career options. Discuss disability-related accommodations and strategies. EP

The Starlight
"Parent-Friendly"
- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW
- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made in U.S.A.

Circle #37 or visit www.eparent.com/adinfo

IGNORANCE IS UNMASKED AND STEREOTYPES ARE EXPLORED

IN THIS SUMMER'S UNCONVENTIONAL ROMANCE,

Pumpkin

by Jennifer Kirby

After going through script after script looking for the perfect first project for her film production company, Blaspheme Films, actress Christina Ricci chose *Pumpkin* because of its strong message about preconceived notions, something both the special needs community and she herself have dealt with. In fact, the now 22-year-old star chose "blaspheme," (which is defined by Webster's New World Dictionary as, "to speak profanely of or to") as the name of her company because, Christina explains, "It comes from the fact that people decided that's what I was without knowing me. Just the idea that you take something that may appear in some way outwardly offensive and you think that it really is offensive all the way down to its core."

> **Just the idea that you take something that may appear in some way outwardly offensive and you think that it really is offensive all the way down to its core.**

Although the young star made her debut as Kate, the endearing younger sister of troubled and confused teen Charlotte in 1990's *Mermaids*, the Santa Monica, California native became equated with her dark and dangerous roles beginning with Wednesday in *The Addams Family*. While she admits to being interested in darkness and where it comes from, she has set out to prove that her range far exceeds that of the Goth actress everyone has labeled her to be, and to simultaneously send powerful messages about society. In *Pumpkin*, the star accomplishes both.

While Christina was originally interested only in co-producing the quirky art house film with Francis Ford Coppola's American Zoetrope production company, she was so taken by the script that she decided to go after it and ultimately landed the female lead as Carolyn McDuffy. "One of the things I liked so much about the script," Christina explains, "is that it was non-judgmental, though it was about two people normally judged so readily: a perfect sorority girl and a physically and mentally challenged boy."

And so, after dying her naturally dark hair blond, Ricci transformed herself into a wealthy sorority sister, whose upbringing and thus far "perfect" life has ingrained in her twisted ideas

Christina Ricci as Carolyn McDuffy and Hank Harris as "Pumpkin" Romanoff.

about the social standing of all others unlike her. However, it is when her sorority, Alpha Omega Pi, attempts to unseat its rivals, Tri Omega, from their 22-year hold on "Sorority of The Year" that Carolyn is forever changed.

Alpha Omega Pi plans to win over Southern California State University's Greek Council by not only extending invites to minority students, but also volunteering their time to assist athletes who have varying special needs and are training for the "Challenged Games" (Hollywood's version of the Special Olympics). Carolyn becomes squeamish over the notion of the latter and voices her opinion, but is immediately overruled.

Reluctantly accepting her assignment to help coach "Pumpkin" Romanoff, a good-looking discus thrower who has mental retardation and motor difficulties (played by Hank Harris), she is initially disgusted and afraid of her protege. However, it is not long before she sees him as the person he is, beyond his disability.

The relationship develops and, to the dismay of both her sorority and her chiseled tennis star beau, Carolyn falls in love with the innocent and sweet-natured athlete. Pumpkin in turn sees beyond Carolyn's appearance, and much to the shock and confusion of his mother, shows that he is capable of sexual feelings and love.

Christina, who is currently working on a yet-to-be-titled Woody Allen film, always looks for one element when it comes to scripts.

"I guess it sounds silly, but I think I take the parts I do because I want to make people aware of things. I wish that certain things were acceptable that aren't. A friend of mine, Kevin, is always saying to me, 'All right, Christina, you're not Nietzsche,' because I do get a little highfalutin with my beliefs," she explains. "But it boils down to the fact that I hate condemnation, and I hate when people who don't fully understand someone else say that they're wrong. So I want to play characters who initially make you go 'Ugh!' and then make you understand those characters, so that if you met someone like them, you wouldn't be so quick to judge them. I don't mean to sound self-righteous. I just hope that maybe I can teach people something from what I do."

According to the Alabama Pumpkin Association, it takes about 90-120 for a pumpkin to grow, days depending on both the variety and climate. With the way it makes fun of ignorance and stereotypes, dispels the idea of perfection and shows individuals who have special needs as productive, functioning human beings, Christina hopes that with *Pumpkin* she, her fellow cast members and filmmakers, have at the very least, planted some seeds of thought in the minds of critics and audiences alike. EP

Reluctantly accepting her assignment to help coach "Pumpkin" Romanoff, a good-looking discus thrower who has mental retardation and motor difficulties (played by Hank Harris), she is initially disgusted and afraid of her protégé.

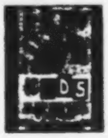
WWW.EPLIBRARY.COM

EP LIBRARY

Exceptional Parent

THE SPECIAL NEEDS BOOKSTORE

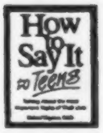
PARENTING



How to Say It to Your Kids
The Right Words to Solve Problems, Soothe Feelings, and Teach Values
Dr. Paul Coleman

This insightful and beautiful parenting manual is filled with a wealth of information that you can immediately use to transform your children's lives. It accurately predicts the traps many fall into and offers practical and sensible advice for dealing with many issues parents face when raising any child.

PH1773PA $14.00



How to Say It to Teens
Talking About the Most Important Topics of Their Lives
Richard Heyman, Ed.D.

If men are from Mars and women are from Venus, then teenagers are from an entirely different universe. Here you'll discover surprisingly easy ways to keep the lines of communication open throughout your child's turbulent adolescent years.

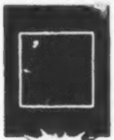
PN1889PA $16.00

The Don't Sweat Guide for Parents
Reduce Stress and Enjoy Your Kids More
Richard Carlson, PhD

This insightful guide provides suggestions for enjoying your children more while being less stressed and more present with them in every moment of their lives. Strategies that are discussed include admitting that you could use some help, learning to take a breather, keeping the job at the office, and many more.

TW7184PA $10.95

FOR YOUNG PEOPLE



NEW

Never Sell Yourself Short
Stephanie Riggs
with photographs by Bill Youmans

Josh is a stereotypical teenage boy. He plays sports, spends time with his friends, and can't wait to drive. Josh is also short statured, and in this inspiring essay he talks about life in a world that is scaled for people much taller than he. His story is inspirational for everyone with obstacles to overcome in order to chase their dreams.

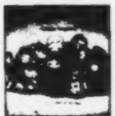
AW5630YP $15.95

NEW

Allie Learns About Alzheimer's Disease
A Family Story About Love, Patience, and Acceptance
Kim Gosselin
with illustrations by Tom Dineen

This touching story about a girl and her relationship with her grandmother who suffers from Alzheimer's Disease is an excellent way for parents to introduce such difficult topics such as family healthcare to their children.

JB3159AZ $14.95

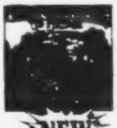


NEW

Special People Special Ways
Arlene Maguire; Illustrated by Sheila Bailey

This book presents a positive image of persons with disabilities using a delightful rhyme and rich watercolor illustrations. It shares the message that even though each of us may have something different about us, we share many commonalities.

FK7651GN $14.95



NEW

Taking Cystic Fibrosis to School
Cynthia S. Henry
with illustrations by Tom Dineen

This heartfelt children's story helps to explain for kids and their parents what cystic fibrosis is, how it is treated, and what activities children can participate in with others.

JJ3094YP $11.95

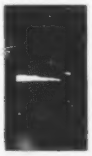
IT'S HERE!!!!
Never Pay Full Price Again with The EP Preferred Buyer Club!! See pg. 82 for details on how to JOIN TODAY!

EPILEPSY

Epilepsy: The Facts
Second Edition
Anthony Hopkins and Richard Appleton

This excellent book is designed to present the facts about every aspect of epilepsy in a clear and consice manner. Written by a neurologist, it presents a clear definition of epilepsy, the different types of seizures associated with the disorder, the medical and surgical therapies used, as well as providing practical points on living with epilepsy

OU5489EP $19.95



Brain Development and Epilepsy
Philip A. Schwartzkroin, Solomon L. Mosh, et al.

This integrated volume applies the emerging concepts in development neurobiology to an understanding of the origins of the epilepsies of childhood. This practical text covers age specific epliepsies, experimental approaches and therapies, and the integration of such knowledge to help formulate a plan to assist in effective treatment for these often devastating syndromes.

OU8462EP $59.95

Partial Seizure Disorders
Help for Patients and Families
Mitzi Waltz

A no-nonsense step by step book that offers an approach to partial seizure disorders based on the latest medical research as well as personal experiences of people with the disorders. Inside you will learn how to obtain an accurate and complete diagnosis, how to cope with the diagnosis, and what treatment options are available.

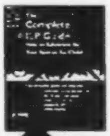
OA0033EP $18.95

IEP

Planning For Success
The College Application Process for Students With Learning Disabilities

The college admission process can be a confusing and overwhelming experience for students with learning disabilities and their families. This comprehensive video enables you to see the college application process from the very beginning. It shows early planning, college visits, the essays, and how to choose the best school for you.

LD201LB $79.99



The Complete IEP Guide
How to Advocate for Your Special ED Child
Lawrence M. Seigel

A comprehensive step by step guide through the entire IEP process that provides encouragement to the reader as it takes a complicated process and makes it easier to understand. Provides instructions, suggestions, strategies, resources, forms and much more.

NL001SE $24.95

NEW
THIRD EDITION

How To Write An IEP
John Arena

Parents, teachers, administrators and others involved in IEP preparation and implementation will profit from this brief, easy-to-use, handbook. This text will serve as an invaluable reference for making sure all factors of consequence are given the consideration they require.

NI200SE $19.95

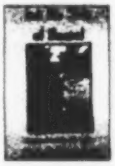
ASPERGER SYNDROME

NEW

Beyond The Wall
Personal Experiences with Autism and Asperger
Stephen Shore

This book provides an interesting, well-written, and insightful autobiographical account of the life of a person with high-functioning autism/Asperger Syndrome. In a way that only one who has been there can, the author offers valuable information that will be of assistance to anyone coping with Asperger Syndrome.

AA1486AS $19.95



Just This Side of Normal
Glimpses into Life with Autism
Elizabeth King Gerlach

This mothers story captures the challenges of raising a child with autism. She can touch her son, Nicky, but not connect with him; hear but not understand his chanted phrases. Yet she embraces life-the joy and sorrow, hope and despair, frustrations and fear without flinching. This story testifies to the power of a heart that has broken wide open.

FL101AT $19.95

Pretending to be Normal
Living with Asperger's Syndrome
Liane Holiday Willey

This book peers under the umbrella of autism and looks at AS, a relatively new less debilitating autism-related diagnosis. Although first discovered in 1944, not much information has become available until the early 1990s with the establishment of a diagnostic criteria set forth by Gillberg and Gillberg. Here is shown that AS individuals are a bright thread in the tapestry of life and our civilization would be extremely dull and sterile if we did not have and treasure individuals with the condition.

TF250AS $17.95

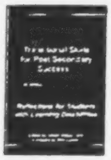
EP LIBRARY • (800) 535-1910 • EPLIBRARY@AOL.COM

PHYSICAL DISABILITY

NICK JOINS IN
JOE LASKER
A free, appropriate public education is guaranteed for all handicapped children and whenever possible, they will be educated alongside non-handicapped children, a practice known as "mainstreaming". This book may help overcome child's apprehension.
AW11800 **$14.95**

YES YOU CAN !!!
Go Beyond Physical Adversity and Live Life to its Fullest
JANIS DEITZ, PHD
Embracing the premise that life should be lived to its fullest, disability or not, this book presents ways for anyone to weather challenges, illnesses, or disabilities. An energetic and zest-filled read, the book will leave you with a "can-do" attitude.
DE348XPD **$15.95**

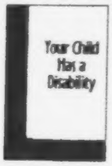
LEARNING DISABILITIES



TRANSITIONAL SKILLS FOR POST SECONDARY SCHOOLS
Reflections for Students with Learning Disabilities
RICK LAVOI AND T. CITRO
A thorough, extensive resource that will prove to be an invaluable guide for parents and students with learning disabilities. This book not only helps students make the transition from the protective environment of home to the university campus but offers a roadmap, for making that transition, and the college years that follow, a success.
LD7110LD **$24.99**

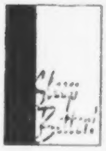
A LITTLE EDGE OF DARKNESS
A Boys Triumph Over Dyslexia
TANYA FALUDY AND ALEXANDER FALUDY
This book combines in one volume a biography and auto-biography. It tells the story of Alexander's life to date from a double perspective: the author, as he gradually became aware of Alexander's strange combination of dyslexic handicap and exceptional intellectual ability: and Alexander's as he recounts first hand the isolation felt by a child who, whilst appearing physically normal, was progressively and puzzlingly rejected. The six chapters covers from birth to college.
TF35740Y **$17.95**

GENERAL



YOUR CHILD HAS A DISABILITY
MARK L. BATSHAW, M.D.
When a child is diagnosed with a disability, parents can be overwhelmed by day to day physical and emotional demands. This comprehensive volume offers some welcome assistance with expert advice on a wide range of medical and educational issues.
PR160LD **$24.95**

PATHWAYS TO LEARNING IN RETT SYNDROME
JACKIE LEWIS AND DEBBIE WILSON
Parents and Teachers of girls with Rett Syndrome will welcome this extraordinary book that offers accessible advice on the special education needs of these girls. It also assists teachers in developing a working knowledge of the syndrome and suggests particular strategies in planning a curriculum which may help overcome the specific difficulties within the diagnosis.
TF533XRS **$26.95**



SLEEP BETTER
V. MARK DURAND PH. D.
This text begins with a discussion of sleep followed by a description of a range of sleep problems and includes a step by step interview that will help you identify the type of problems being encountered. Includes treatment options covering bedwetting, sleep walking, insomnia and much more.
PB166GN **$23.95**

AUTISM

AUTISM AND THE NEW LAW
Resources for Treatment, Hope for Cure
NARRATED BY: ANTHONY EDWARDS
This 30-minute video is designed to help parents, educators, and health care professionals better understand Autism or similar diagnosis such as PDD and Asperger Syndrome. Learn about the components of The Advancement of Pediatric Autism Research Act and how it affects the lives of you, your child, and your family.
EV6882AT **$49.95**

FRAGILE SUCCESS
Ten Autistic Children, Childhood to Adulthood
VIRGINIA WALKER SPERRY, M.A.
In this book you will get a view of autism in all its variations as the author, a ormer teacher, traces the lives of her students over 30 years These true case histories provide exceptional insight into the mystery and diversity of autism.
PB4587AT **$24.95**

RAISING A CHILD WITH AUTISM
A Guide to Applied Behavior Analysis for Parents
SHIRA RICHMAN
Applied Behavior Analysis (ABA) is increasingly recognized as a highly effective way of helping children with autistic spectrum disorders. The author explains how parents can adapt the practical techniques used in ABA for use at home, providing tips and advice for families and parents.
TF9106AT **$19.95**

A WORK IN PROGRESS
Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism
RON LEAF AND JOHN MCEACHIN
A superb collection of ideas and programs for building skills as well as strategies for dealing with challenging behaviors. It is a comprehensive guide presented in user-friendly language so parents and professionals can easily understand and use this valuable resource.
DR6600AT **$42.95**

DYSLEXIA

DYSLEXIA, FLUENCY, AND THE BRAIN
MARYANNE WOLF
Consider the time it takes for the brain to process written language. What impact does the brain's processing time have on reading, development? What are the relationships among processing time, reading fluency, and dyslexia? Can time and fluency related problems be changed? How should intervention be designed to address the issue. This monumental resource presents evidence indicating that many dyslexic children have a second core deficit in rate of processing linguistic differences in multiple areas. This book has been constructed to bring several levels of evidence and types of research to bear on these questions.
YP2602DY **$30.00**

LEARNING ABOUT LEARNING DISABILITIES
Second Edition
BERNICE WONG
Targeted for the advanced student and professional this text covers a wide range of topics to ensure a comprehensive and balanced coverage of important areas in learning disabilities. Included are conceptual issues, basic research in memory processes and social aspects of learning disabilities intervention research in academic areas and nonacademic areas, issues in service delivery and a life span perspective.
ACP5321LD **$59.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: **EP**, Dept. EP0802, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call **800•535•1910**

QTY.	ITEM#	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item
Foreign – $7.00 for 1 item; 75¢ for each additional item

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

These prices are subject to change without notice.

Name ______________________________
Address ______________________________
City ______________________ State __________ Zip __________
Telephone ______________________ E-Mail ______________________
I have enclosed my check payable to EXCEPTIONAL PARENT or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover
Account Number: ____-____-____-____ Exp. Date ____/____
Signature ______________________________

Circle #200

E-Buddies

E-Buddies, the newest program within Best Buddies International, provides online friendships for people with and without mental retardation. The program pairs people based on similarities in age, interests, and gender, offers a safe way for people with disabilities to make friends and helps build communication and motor skills. E-Buddies, which began in October 1999, only requires that each participant be capable of communicating via computer and complete a screening process.

BEST BUDDIES®

For more information visit: http://www.ebudddies.org

WHO DO YOU THINK YOU'RE KIDDING?

Ziggy

The comic strip icon Ziggy has recently been named the official spokescharacter for the Leukemia & Lymphoma Society. Ziggy, the iconic "everyman" whose philosophical outlooks bring humor and hope to thousands of readers across the country, will exemplify the ideals of the Leukemia & Lymphoma Society, which gives a sense of optimism to thousands of people with blood-related cancers and their families.

Hugs and Hope

Hugs and Hope is a non-profit organization dedicated to bringing joy into the lives of critically ill or injured children. Based in Harshaw, WI, this foundation of more than 300 volunteers sends toys, cards, books, and stickers to sick children. To view stories, pictures, and prayers for the children, or find information about how to get involved or to send donations, visit their website, http://www.hugsandhope.com.

Anne Ford Scholarship

The National Center for Learning Disabilities has chosen Troy G. Sponaugle II of Fairfax, VA, as the inaugural Anne Ford Scholar. The Anne Ford Scholarship program provides $10,000 over four years to a promising high school senior with learning disabilities who plans to pursue a university degree. For more information, or to apply, visit http://www.LD.org.

Report to Congress

The 23rd Annual Report to Congress on Special Education released its results in June. Graduation rates for students with disabilities were higher and dropout rates fell over five percent since 1997. Integration of students with disabilities in regular classes was at a record level. The report also showed that students with autism had the lowest dropout rates, while students with emotional and behavioral disorders had the highest. To read the entire report, visit: www.edu.gov/offices/OSERS/OSEP/Products/OSEP2001AnlRpt.

Osgood-Schlatter on the Rise

As the participation of young girls in athletics increases, so does the occurrence of knee injuries previously seen mostly in boys. One such example is Osgood-Schlatter disease, an inflammation due to overuse that often occurs during a child's rapid growth period. Home treatment for the disease focuses on alleviating pain through typical first aid; decreased activity is advised. In many cases, Osgood-Schlatter disease may go away on its own if given enough time and rest.

More information can be obtained from the following web sites:

- http://familydoctor.org/handouts/135.html
- http://orthoinfo.aaos.org/fact/thr_report.cfm?Thread_ID=145&topcategory=Knee
- http://www.physsportsmed.com/issues/1998/03mar/wall_pa.htm

Special Toys for Special Kids

Learning Express, a leading specialty toy retail franchise chain based in Ayer, MA, is developing a program to help its sales personnel assist parents of children with disabilities.

Led by its new president, Joe Diaz, the company is gathering information from a variety of sources to identify toys that can be easily used by children with special needs. "I hope to build on our record of service by being attuned to the special needs of children with disabilities," Diaz says. "By this fall, we intend to train every staff member in at least one toy or education category about the specific products that are especially useful to children with disabilities."

Learning Express is contacting organizations and publishers such as EP to provide the background and evaluation that will form the basis of this program. Founded in 1987, Learning Express currently has more than 130 stores operated by independent franchise owners in thirty-five states.

Visit http://www.learningexpress.com for more info.

BEST COPY AVAILABLE

Learning Express®

www.learningexpress.com

Learning Express, your neighborhood toy store, is pleased to assist Exceptional Parent in their efforts to increase awareness of exceptional children with special needs.

Visit us online at www.learningexpress.com to find a Learning Express store near you.

Your Neighborhood Toy Store

BEST COPY AVAILABLE

Circle #70 or visit www.eparent.com/adinfo

NEVER PAY FULL PRICE AGAIN!!

EP PREFERRED BUYER CLUB OFFER!

EP PREFERRED BUYER CLUB!!

A Charter Membership in the EP Preferred Buyer Club includes the following special benefits:

- A personalized EP Membership Card
- 10% Discount on all books in the EP Library
- 10% Discount on all videos in the EP Library
- 20% Discount on all EP Monographs and Special Reports
- $7.50 Discount on annual subscription to EP Magazine or renewal during term
- One free ticket to the World Congress Exposition on Disabilities
- Gift Certificate for FREE SHIPPING on next order
- Only $24.95 per year

Take advantage of this dynamic offer now!
You can sign up any one of the following ways:
CALL 800-535-1910 or Visit
www.eparent.com & www.eplibrary.com

YES!! I want to join the EP Preferred Buyer Club so that I won't have to pay full price again !

Mail to: Exceptional Parent Dept: Membership P O Box 1807 Englewood Cliffs, NJ 07632-1207
Or Order on-line: www.eplibrary.com/epreferredbuyerclub/ Fax (201-947-9376 Or call 800-535-1910

Name: ____________________
Address: ____________________
City: __________ State: ______ Zip Code: ______
Telephone: __________ Email: __________

I have enclosed my check payable to Exceptional Parent or charge to my:

☐ VISA ☐ Mastercard ☐ AMEX ☐ Discover

Account Number: ____-____-____-____ , Exp. Date: __/__ Signature:

For Further Reading...

by Megan Henninger

Trying to find the proper person to care for your child or yourself? Not sure how best to help a patient? These books offer various viewpoints on healthcare for people with disabilities. To access these and other titles contact the EP Library online (http://www.eplibrary.com), by fax (201-947-9376) or by calling (800) 535-1910.

Caregivers
Personal
Assistants

Caregivers and Personal Assistants: How to Find, Hire and Manage the People Who Help You (Or Your Loved One!) 3rd Edition

By Alfred H. DeGraff, M.A., S.E.A.

EP Library Code: SA0612HC Price: $24.95

This new edition focuses on the RISHTMP cycle (Recruiting, Interviewing, Screening, Hiring, Training, Managing and Parting Ways) that occurs between caregivers and those receiving care, with the underlying theme that understanding everyone's goals will improve the quality of care.

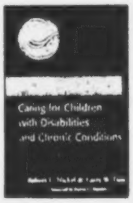
GETTING INVOLVED IN
CHOOSING STAFF

Getting Involved in Choosing Staff: A Resource Pack for Supporters, Trainers and Staff Working with People Who Have Developmental Disabilities

By Townsley, Howarth, LeGrys & Macadam

EP Library Code: HT6118HC Price: $55.00

Designed for professionals involved in hiring staff to support a group of people with developmental disabilities, this resource explains why and how persons with developmental disabilities can be involved in staff selection.



The Physicians Guide to Caring for Children with Disabilities and Chronic Conditions

By Robert E. Nickel & Larry W. Desch

EP Library Code: PB4463HC Price: $125

Opening chapters of this reference outline basic service needs, developmental screening and surveillance, working with families and the importance of nutrition and growth. Subsequent chapters cover specific medical conditions including developmental disabilities, mental retardation, cerebral palsy, autism, visual/hearing impairments, anxiety disorders, prenatal drug exposure, neural tube defects, craniofacial disorders, traumatic injury and chronic respiratory disorders.

Zooperb.

Kids love the Tigers, Turtles, and other creatures in this line of extraordinary therapeutic equipment. Distributed exclusively by Bodypoint Designs, Jenx™ has created a revolution in the evolution of children's positioning therapy.

Built with a unique tilting seat, Jenx Prone-angle™ sitters put your child in a more functional position, encouraging reaching and extending, helping them with upper extremity and head control.

Designed for children 9 months to 7 years, this new "species" of superb therapeutic equipment brings the support needed to their bodies, as well as a smile to their souls.

So, next time you need to position a child for success, introduce them to Jenx. Zooperb in every way.

JENX
Distributed by
BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104
In Canada, call Advanced Health Care Products. Tel: 800-265-9830

Circle #22 or visit www.eparent.com/adinfo

JUSTINE

Justine Lydiana Rosario, 7, shared a lot of love with her baby brother **Jordan**, 1, this past Valentine's Day. Justine has hydrocephalus, a VA shunt, Dandy Walker malformation, facial hemangioma and is developmentally delayed. She lives in sunny Florida with her brother and parents, Gary and Nancy.

BRANDON

Brandon, 4, and his sister **Shirley, 11**, pose here with Santa Claus. Brandon had fetal distress when he was born. This resulted in cerebral palsy. He doesn't talk, crawl or sit, but is constantly a happy boy who is full of smiles. He loves to watch television, especially Blue's Clues and Barney, and also enjoys being read to by his mom and dad. Brandon attends Laremont School where he receives OT, PT and speech therapy. His favorite day is Wednesday, as that's his day in the pool for swimming therapy. Marie and Susan (his teachers) and riding the school bus are also among his favorite things. Brandon lives with his parents, Gladys and Donald, and his big sister Shirley. Shirley loves him a lot and plans to be a doctor to treat kids with cerebral palsy.

MATTIE

Pictured above are **Audrey** and her brother **Mattie Davis**, who has bilateral periventricular nodular herterotopia(BPNH) and a "patch" of polymicrogyria. Mattie, two and a half years old, enjoys reading books - especially Clifford, Barney, and Pooh - listening to all types of music, and using the "Jumpstart Baby" program on the computer. He attends the Summit (NJ) Speech School's EI Program where he is learning to take steps on his own. Mattie uses PEC cards to make choices and is now able to say "yes" by clapping his hands.

DEIONA

Deiona Nicole Jones, 3, has Down syndrome. However, this does not prevent her from being a "little princess" around the house. She has 3 older brothers, Aaron, Brandon and Cameron, and she attends the PEEP program (Program for Educating Exceptional Preschoolers), held at Lee Hall Elementary in Newport News, VA. Deiona lives with her parents, Valor and Anthony Jones, on Fort Eustis, VA.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (EXCEPTIONAL PARENT), 65 E. Route 4, River Edge, NJ 07661. (Please do not send "one-of-a-kinds" as we regret that **photos cannot be returned.**) On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

BEST COPY AVAILABLE

Record Keeping for the Medically Complex Child:

Having the Answers Ready

by Barbara Robbins

As primary caregivers, parents are an essential part of their children's healthcare team. No one knows them better than the person who loves them and takes care of their day-to-day needs. However, for the medically complex child, knowing and loving may not be enough in a crisis. When medical personnel ask parents for vital facts, a mistake or omission can have serious consequences, but the risk can be minimized by a method of record keeping I've found helpful with our son.

In July 1984, God blessed our family with a precious baby boy we named David. We soon realized that David was not developing normally, and at the age of three months he was hospitalized for neurological testing. While there he began having massive infantile spasms, a severe seizure disorder which resulted in profound mental retardation (see "Infantile Spasms," EP, September 2001). David was also diagnosed with cortical visual impairment, leaving him legally blind. We went home facing a frightening and uncertain future.

Pictured above is David Robbins whose rapidly changing condition inspired his mother to create the Medical History Notebook.

After three stressful months and many trips to the hospital, David's condition stabilized. As a family, we settled down into a routine. With frequent medical appointments, therapy sessions, daily home exercises, and several hours spent each day meeting David's needs, we had little free time.

As David grew, his condition became increasingly complex. When he was three years old he lost his ability to feed orally, and had surgery to put in a permanent feeding tube. Involuntary spasms in his muscles made David's joints rigid. Some of his joints became fixed with contractures and would not move at all. Gradually, muscle spasms resulted in curvature of his spine. David's fragile bones, weakened by lack of weight bearing, began fracturing. By the age of 8 David was in the hospital at least once a year.

X-rays when he was 12 years old showed that David's diaphragm was partially paralyzed. This resulted in breathing problems and the need for continual oxygen therapy, respiratory treatments and suctioning.

His rapidly changing condition opened my eyes to some gaps in my ability to be a useful member of David's healthcare team. Each time he went into the hospital, I faced a frustrating array of medical background forms whose completion was daunting. And I had trouble explaining some of David's rare medical conditions to the residents and nurses, because I didn't fully understand them myself. The need for some study and for a written record of David's medical history became obvious.

I began reading everything I could about David's special needs. I found one book extremely helpful: *Cerebral Palsy: A Complete Guide for Caregiving*, by Freeman Miller, MD and Steven J. Bachrach, MD (Johns Hopkins University Press, Baltimore, 1998). It provided a wealth of information that helped me to make sense of what was happening with David, and a section on hospitalization offered a guideline for compiling a brief record of a child's medical history. Starting with this guideline, I put together a loose-leaf notebook containing the basic information that was needed whenever David saw a new doctor or was admitted to the hospital. Though they were many, I believe the hours used assembling the original book were some of the most beneficial I've ever spent.

Through the years, I've updated David's medical history record periodically. By keeping it as a computer file, I can easily do this when his condition changes, medications change, or he is hospitalized, then print the new pages and add them to the notebook.

Thus I can quickly access the information needed to fill out hospital admitting forms. By now, staff in the emergency room and in the unit where

BEST COPY AVAILABLE

Almost every time David is hospitalized, at least one doctor or nurse tells me they wish all parents would keep such a notebook, because it makes their job much easier.

David is usually admitted often don't ask me to fill out forms. They simply ask for the notebook and make copies of the information they need for their records. Almost every time David is hospitalized, at least one doctor or nurse tells me they wish all parents would keep such a notebook, because it makes their job much easier.

The content of a medical history record will vary, depending on the needs of the child. Some of the basic data to include are listed below. Not all of the following areas may apply to your child, and others not discussed here may need to be included.

Title page: **Patient's name**
Social Security number
Insurance identification number

All immunizations, with dates. I've also included TB tests and results in this section. It can also help if reactions to any immunizations are noted.

Drug allergies and reactions. Include the name of the drug, specific allergic reaction, and (if available) the date of the reaction. I also list drugs to which David has had a reaction after prolonged use, in a separate list following the drug allergies. Though these are not considered actual allergies, this information can be useful. You may also find it helpful to include other allergies, such as latex, specific foods or adhesive tapes.

List all medical problems and diagnoses. I began with a primary diagnosis, then listed each of David's specific medical problems. Since I use this notebook with both medical and non-medical providers—teachers and school administrators, mental retardation professionals—I've included a brief explanation of each medical diagnosis. I also have included information on medications that have been

BLADDER CONTROL PRODUCTS

Snuggems
HUGGIES Supreme
Pull-Ups
GoodNites

Call for your free incontinence products catalog and receive a FREE $25 gift* with your first order.

DMP DURALINE

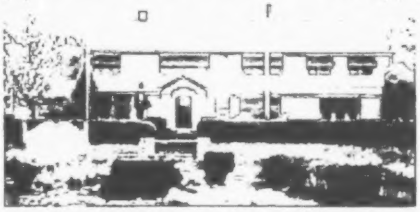
1-800-654-3376

www.dmponline.com

* Offer expires December 31, 2002. Available only to new customers, with a cash or credit card purchase over $35. Not valid with other offers. $25 gift is not pictured above.

10662

Circle #69 or visit www.eparent.com/adinfo


Crystal Springs School

A PROGRAM OF THE
Institute for Developmental Diabilities, Inc.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeastern Massachusetts, close to Boston, Cape Cod, Providence and Newport, RI.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, Including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availablity.
- Licensed by the MA Office of Child Care Services.
- Approved by the MA Department of Education.
- Member of the MA Association of Approved Private Schools.

For information, Please Call Our Admissions Coordinator:
1-800-840-8087 **(508) 644-3101 Ext: 375**

Circle #29 or visit www.eparent.com/adinfo

used in treating David's seizures, dates and details of fractures, and dates he's had pneumonia.

Routine medications. Necessary information includes dosage and frequency. If you want the hospital to follow your home medication schedule, times should also be included. Medications come in different strengths, so be sure to list the actual dosage. For example, phenobarbital, a common seizure medication, comes in 15 and 30 mg tablets and in two different liquid strengths. Noting merely "give one tablet twice a day" or "give 5 ml three times a day" can result in an incorrect dosage.

Medical treatments. Include the schedule of treatments, settings for any equipment used, descriptions of treatments (such as number of cycles, medications used, or supplies used) and any other related information. My son is tube-fed, so I've also included information about his feedings (date current feeding tube was put in, brand and size, feeding method, amount and kind of formula). For home use, an equipment maintenance schedule can also be helpful.

Doctors. Include the name, medical specialty, address, phone number, fax number, email address and cell-phone number. The same contact information is needed for the nurse, nurse practitioner, physician assistant and others in the doctor's office. If available, the date when you began seeing the doctor can also be helpful, along with the recommended frequency of visits and the date of the last visit.

Agencies and medical supply companies. Include school contact information, nursing or other healthcare agency information, social agencies, contact numbers for ordering supplies and medications, etc. Something I've found helpful for use at home is a list of standard supplies, upon which I can record the quantity of each item ordered, date ordered and date received.

Height and weight chart. This can be done as a list, or in the form of a graph.

Surgeries. Include the date, where performed, the name of the surgical procedure (eg, device implantation, selective dorsal rhizotomy), whether it was done as inpatient or outpatient, the doctor who did the surgery, and any other relevant information. Time spent in the hospital, for example, might be needed for reimbursement.

Hospitalizations other than surgeries. Include the dates of admission and discharge, where hospitalized, the admitting doctor, the reason for hospitalization, and any test results to which you need to refer.

Trips to the emergency room and even scheduled hospitalizations can cause great anxiety to the medically complex child and to the parents. In a stressful situation, it's natural to forget important information, but with a medically complex patient a mistake can be a matter of life and death. It is crucial to have accurate information about the person. A compact medical history record puts facts at your fingertips, ready to access whenever needed. EP

Barbara Robbins and her family make their home in Houston, Texas.

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number, and e-mail address! ***Now on the Web!*** We will now be including **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on theEPWeb site, exactly as they appear in the magazine and with the same text.

Get More Out of Vestibular Stimulation with The Motion Table

The Motion Table enables therapists to deliver the value of vestibular motion to their patients without the need for constant hands-on intervention.

Most stimulation equipment available today reduces the therapeutic effect of *horizontal motion* by incorporating rounding, swinging and tilting motions. **The Motion Table**, through its smooth, "vibra glide" movement provides a steady, uniform stimulation that can help "level out" extremes in patients' behavior.

And, since **The Motion Table** is motorized, patients can be stimulated for longer periods than is possible with manual equipment.

The Motion Table comes in several sizes and is available from RedBarn Enterprises, a leader in innovative solutions for therapists and their patients.

The Motion Table reduces...
- *Hypersensitivity*
- *Self-abuse*
- *Abnormal Muscle Tone*
- *Constipation*
- *Pulmonary Congestion*

The Motion Table increases...
- *Concentration*
- *Attentiveness*
- *Calmness*
- *Body Awareness*
- *Postural Control and Balance*

Try The Motion Table AT NO RISK for 30 days.
Try it for a month. If you're not completely satisfied, just send it back for a complete refund

For a copy of a just-released Technical Evaluation of The Motion Table or additional product information, call us at 1-800-577-1317, or visit us on the Worldwide Web at www.redbarn-enter.com.

RedBarn ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.redbarn-enter.com**

Circle #52 or visit www.eparent.com/adinfo

Research Reflections....this time from abroad

Latest International Research on Intellectual Disability Bodes Well for Families

Her Excellency, Mary McAleese, President of Ireland (center) amid staff and self-advocates.

This article summarizes some of the exciting research presented at the International Association conference of the Scientific Study of Intellectual Disability (IASSID). The meeting was held in Dublin, Ireland, from June 12–15, 2002. As co-chair of the division presenting research on families, and one of the conference's Plenary Speakers, Dr. Jan Blacher had an inside view of some conference highlights.

This Inaugural Conference of IASSID Europe was held in order to promote scientific exchange and understanding throughout the many countries of Europe. Speakers came from 25 European countries, as well as from the U.S., Canada, Australia, Taiwan and Israel (considered "honorary" European nations for the purposes of this conference).

All in all, families who have a member with intellectual disability (ID) have many reasons to be hopeful about the immediate future. I'd like to begin by sharing some predictions with you from the organizers of this inaugural IASSID. I asked them, "How will parents of children and adults most benefit from the scientific study of intellectual disabilities?"

Dr. David Felce, Professor at the Welsh Centre for Learning Disabilities, University of Wales, listed multiple roles for parents in the conduct of research on ID. Parents may:

- suggest, or even decide, research priorities;
- learn from, or be consumers of, research findings;
- be directly involved in the conduct or process of research;
- interact with other members of IASSID to improve understanding and collaboration.

And from Dr. Patricia Walsh, Professor of Disability Studies at University College, Dublin:

"I've seen and assisted parents as they encounter the courts, lawyers, government ministers, service providers and the press here in Ireland for many years now. In each

Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, where she has been a researcher for 20 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of mental retardation, dual diagnosis and the transition to adulthood. Dr. Blacher has developed **Research Reflections** as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to **Research Reflections** and any suggestions you might have. Send e-mail to: jan.blacher@ucr.edu.

BEST COPY AVAILABLE

case, progress inches forward most surely when the initiators can draw on sound evidence – and that's what IASSID can deliver – at least on a good day."

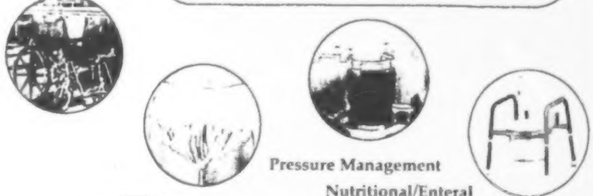
At the meeting, I conducted interviews with several of the key figures, posing the main question: ***What are the most pressing research issues pertaining to intellectual disability, internationally speaking?*** There was some consensus among responses, centered around the implications of epidemiological trends and research in genetics, living environments and social integration.

Epidemiological trends. Dr. Chris Hatton, Research Director at Lancaster University in the United Kingdom, responded that epidemiological trends concerning people with ID are bringing new issues to the research forefront. He notes that across the U.S., Canada, Europe and Australia, ethnic and cultural diversity are increasing, and that it behooves researchers to conduct studies that are representative of, and applicable to, all persons with ID. Family researchers are taking steps in this direction, as reflected in the following papers given at the conference: *Child disability, parental coping and parental mental health in UK South Asian families with a child with severe intellectual disabilities* (Chris Hatton, Yasmeen Akram, Robina Shad, Janet Robertson, Eric Emerson, England); *Chinese immigrant families: Coping with developmental disability* (Iris Tan Mink, Kazuo Nihira, Eli Lieber, USA).

The paper presented by Chris Hatton and colleagues reported on data from a survey of 136 U.K. South Asian mothers of children with severe intellectual disabilities. They examined the prevalence of depression and anxiety in this group of mothers, and determined the applicability of current models of family functioning to South Asian families. Rates of parental anxiety (26 percent) and depression (40 percent) were considerably higher than those of South Asian adults in the U.K. who did not have children with disabilities. Anxious mothers were more likely to have a greater range of unmet service needs for the child with ID, and to lack full-time employment (for themselves or for their spouse). Depressed mothers were more anxious, as well, and received less social support, endured cognitive distraction, and experienced a lack of collaborative relationships with professionals. Together, findings suggested that family disadvantages in material, social

continued on page 94

Connetquot West, Inc.
Health Care Products



Pressure Management
Nutritional/Enteral
Specialty Seating
Bathroom Safety
Personal Care
Incontinence
Ambulatory
Respiratory
Urological
Beds/Lifts
Skin Care
Mobility

This month's
FREE SAMPLE FEATURE
Resource Just for Kids
CALL FOR YOURS!

HOME DELIVERY!

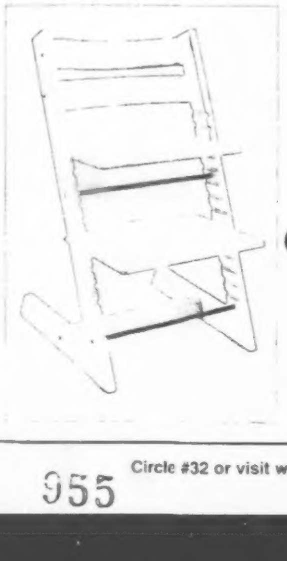
Quality for You. Quality for Life...

Toll-Free: 866-588-3888

Fax Toll Free: 866-588-3337

711-3 Koehler Avenue ○ Ronkonkoma ○ New York ○ 11779
Email: connetquot@aol.com

Circle #26 or visit www.eparent.com/adinfo



We Like Making Kids Happy ...

Send For Free Catalog

equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094
E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #32 or visit www.eparent.com/adinfo

Getting information from

EP advertisers is

MUCH FASTER

ONLINE!

It's as easy as a click
of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE
Information
from Advertisers
CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in EXCEPTIONAL PARENT.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.
   Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
17	ABILITIES EXPO	101
21	ADAPTIVEMALL.COM	60
18	ADVANCED RESPIRATORY	69
67	ALLERGAN	67
19	ANNANDALE VILLAGE	45
22	BODYPOINT DESIGNS, INC.	83
23	CAMPHILL SPECIAL SCHOOL	103
	CHILDHEALTHMONITOR.ORG	97
24	CHILDREN'S HOSPITAL	29
25	COLUMBIA MEDICAL	9
26	CONNETQUOT WEST	89
27	CONSUMER CARE PRODUCTS, INC	60
28	CROTCHED MOUNTAIN REHAB	95
29	CRYSTAL SPRINGS SCHOOL	86
68	CYBERONICS	62-64
	CYCLETOTE CORP.	74
28	DRIVE MASTERS	107
69	DURALINE MEDICAL PRODUCTS	86
30	DYNAVOX SYSTEMS LLC	C3
31	EDEN FOODS, INC.	7
200	EP LIBRARY BOOK CLUB	82
200	EP LIBRARY PAGES	78, 79
41	EP NEWBORN SCREENING DVD	93
199	EP SUBSCRIPTION CARD	17-18
32	EQUIPMENT SHOP	89
33	EVERGREEN CENTER	103
34	FORD MOBILITY	C2
35	FREEDOM CONCEPTS	49
36	FREEDOM MOTORS USA	107
37	GLOBAL POWER SYSTEMS INC	75
38	H.D.I.S.	32
39	HARD MANUFACTURING	16
20	HEARTSPRING	33
40	HMS SCHOOL	50
	HOUSE AD	90
42	INNOVATIVE PRODUCTS	72
43	KIDS #1, INC.	74
44	LAWYERS, INC.	57
70	LEARNING EXPRESS	81
45	LITIGATORS, INC.	19
46	MELMARK	71
47	MET METROPOLITAN LIFE INS.	11
48	MIDWEST MOBILITY AND DESIGN	56
49	OCEAN HYPERBARIC CENTER	61
50	OTTO BOCK	13
51	PATHWAYS AWARENESS FOUNDATION	65
52	RED BARN ENTERPRISES	87
53	ROSS LABORATORIES	53
54	SAMMONS-PRESTON	15
55	SIGMA TAU	1-2
56	SNUG SEAT INC.	5
57	STEWART HOME SCHOOL	72
58	THE BABY JOGGER COMPANY	50
59	THE CENTER FOR DISCOVERY	51
60	THE NYU HOSP FOR JOINT DIS CTR	44
61	ULTRAFLEX SYSTEMS, INC.	103
62	VAIL PRODUCTS	C4
66	VANTAGE MOBILITY	55
63	VERIZON	47
64	WOODBURY PRODUCTS	56
65	WORLD CONGRESS	38-41

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

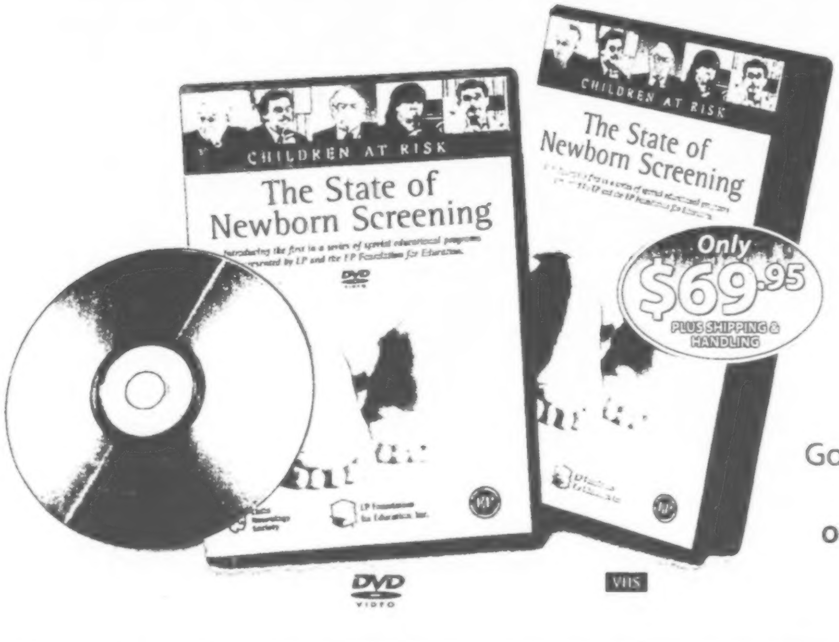
EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged.
The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms.
300 North Zeeb Road, Ann Arbor, MI 48106

What is Universal Newborn Screening?

This could help change the
quality of your child's life



EP Foundation for Education, Inc.

Child Neurology Society

Go to: www.eparent.com
for more information

ORDER THE DVD NOW!

Darryl DeVivo, MD SIDNEY CARTER PROFESSOR OF NEUROLOGY COLUMBIA UNIVERSITY	*Piero Rinaldo, MD, Ph.D.* DIRECTOR, BIOCHEMICAL GENETICS LABORATORY MAYO CLINIC	*Edwin Naylor, Ph.D.* PRESIDENT NEOGEN SCREENING, INC.	*Joan E. Pellegrino, MD* ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES UMDNJ, ROBERT WOOD JOHNSON MEDICAL SCHOOL	*Paul M. Fernhoff, MD* MEDICAL DIRECTOR EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #41 or visit www.eparent.com/adinfo

continued from page 89

Laura Lee McIntyre, Conference Speaker (left) with Jan Blacher, Plenary Speaker and Chair, IASSID Special Interest Research Group on Families.

L to r: Jan Blacher, Stephen Healy, Secy. IASSID; David Felce, IASSID Europe; Ireland President McAleese and Neil Ross, President, IASSID.

and service supports are crucial factors in determining family functioning in South Asian families, who are a growing population in the UK.

Another epidemiological trend is that the life expectancy of persons with ID is rapidly increasing, and people with severe and challenging needs are often surviving into adulthood and even old age. Dr. Philip McCallion of the University of Albany noted that aging, dementia diagnosis and support of aging caregivers are now critical research issues. These areas were represented by such papers as: *Subjective burdens/ difficulties working with persons with intellectual disabilities and dementia* (Philip McCallion, USA, Mary McCarron, Ireland); *The needs of older people with learning disabilities and mental health difficulties* (Eleni Hatzidimitriadou, Rachel Forrester-Jones, England); *The challenges for supported living as people age and need more diverse support structures* (Margaret Rogers, Mairead Mitchell, N. Ireland).

Genetic research. Recent findings on genetics, in particular those from the Human Genome Project, may help to "explain" aspects of intellectual disability. Researchers who work with people with intellectual disabilities need to appraise and evaluate current genetic research and develop more sophisticated studies to investigate interactions between genetic influences (also called the behavioral phenotype) and the impact of the person's environment. Toward this end, Laura Lee McIntyre of the US presented a paper on *Behavioral disorders, syndrome specificity and family impact* (with Jan Blacher, USA). Findings were presented from 208 English-speaking and 115 Spanish-speaking mothers of young adults (ages 16-26 years) with severe disabilities. Although mothers in the two groups did not differ significantly in age (about 48 years), they differed in all other demographics reflecting social or economic class: employment, income, education, and health, with English-speaking mothers far more advantaged. Yet the percentages of young adults with low, moderate or severe behavioral challenges in the two samples did not differ. Young adults with high behavior problems, associated most strongly with autism, had the most negative impact on parenting. Young adults with Down syndrome were associated with the least negative impact. There were no differences in positive impact on parenting across these genetic subtypes. In addition, the impact of behavioral phenotypes (autism, Down syndrome, cerebral palsy, or other intellectual disabilities) on families was similar across cultural groups, except that Latina mothers reported more overall positive impact. This is the first attempt that we know of to show the effect of behavioral phenotypes across groups that differed widely in cultural context and socio-economic circumstances.

A Presidential Visit

A memorable event at the meeting was an address given by Her Excellency Mary McAleese, President of Ireland. She applauded the efforts of the international researchers assembled, and spoke of their role in putting Dublin on the map and consciences of researchers worldwide. Furthermore, she noted that Dublin would be hosting the Special Olympics in June, 2003, the first time Special Olympics would be held outside of the U.S. Readers of EP, particularly parents, might be pleased to know that Her Excellency emphasized the importance of research aimed at better understanding the experiences and needs of parents and families of persons with intellectual disability. Conference participants were surprised, and delighted, when the President mingled with the crowd after her address, and spent time conversing with some of the self-advocates in attendance. (Participants from the U.S. found this personal touch quite unusual.)

Other investigations of specific behavioral phenotypes and their impact included: *Behavior problems in girls with Rett syndrome* (Richard Hastings, England); *Family predictors of depressive symptoms among young people with Down syndrome* (Stephen Turner, Scotland, Alison Alborz, U.K., Vernon Gayle, Scotland).

Research on living environments. People with intellectual disabilities are living in very different environments from those of 30 or 40 years ago, a situation true in Europe as well as in the U.S. This raises new questions for researchers, of course, such as access to community health care for persons with ID, employment,

958 BEST COPY AVAILABLE

interactions with the legal system and self-determination. It will become more important than ever to identify which residential variables most predict higher quality of life for individuals with ID and their families. Determining quality and costs of residential care continues to be of interest, as reflected in the following papers: *Rational resourcing and productivity in community-based supported accommodation for people with intellectual disabilities* (David Felce, Edwin Jones, Kathy Lowe, Jonathan Perry, Clare Bowley, Wales); *The quality and costs of community-based group homes and village communities for people with intellectual disabilities in Ireland* (Patricia Noonan Walsh, Christine Linehan, J. Durkan, John Hillery, Ireland).

Social and integration issues. There is still much to be learned about social integration of people with ID and with other exceptionalities, and the European conference addressed this in a number of ways. For example, participatory research approaches, whereby the person with ID is an active agent in the research process, are becoming more popular. So, too, are action research approaches, where research is closely linked with local actions for positive change. Some exciting examples included: *Users views in the process of changing an organization* (Jos van Loon, The Netherlands); *Parents of kids with disabilities: How do they try to get more than an invitation to participate?*(Rita Stevens, Hilde Herssens, Belgium); *Self-advocates and research: A fruitful marriage?* (Erik Vriamont, Ludo Schoeter, Belgium).

I couldn't help leaving this gathering of international researchers without pondering the cliché, "small world." Perhaps, though, the world grows ever smaller because the capacities of those who inhabit the earth grow ever larger. So it went in Dublin, where innovative research findings from around the globe expanded our perspectives and knowledge of exceptionality. Wish you were there. ■

For information on contacting speakers or requesting copies of IASSID presentations, please email us at EPEDIT@aol.com or fax us at EP edit, 201-489-0074.

Never in my Wildest dreams...

"WHEN I FIRST CAME TO CROTCHED MOUNTAIN OVER 10 YEARS AGO, activities that were second nature prior to the automobile accident were challenging tasks. Today I am a college graduate and also have my drivers license.

Never in my wildest dreams would I have been able to do half of what I've achieved without the encouragement and help that I received at Crotched Mountain! I want to thank everyone at Crotched Mountain for helping me get my life back!"

—*Brent Reagan '93*
Crotched Mountain School

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@cmf.org

CROTCHED MOUNTAIN OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #28 or visit www.eparent.com/adinfo

Part III: Transitions & The Placement Process - It's All About Choices

by Cynthia Whitfield

INFORMING

EMPOWERING

AND KEEPING PARENTS INVOLVED

While transitioning is rarely an easy process, it is something that most parents of children with disabilities must face. After working hard to find a placement that seems to fit their child's needs, parents are eventually faced with having to move on. Transition to a new program or to the next level of care could be necessary if, for example, the child's IEP doesn't change from year to year, the child stops moving forward or skills begin to regress, the child seems bored by school or the child resists getting on the bus in the morning.

Sometimes these changes are embraced by all involved. In other cases, parents report having the distinct feeling that their child's new teacher isn't exactly thrilled about having to include their special needs child. Sometimes a new placement seems like a step back rather than a step forward, and sometimes the necessary new program placement is not available. But at some point, moving on is unavoidable.

The Center for
DISCOVERY

Gigi Aaron, a consultant on autism, says a well-thought-out transition plan is essential. Besides facilitating placement, she advises teachers and assistants on the best ways to help children become happy and successful in their new settings. Whether the transition is from preschool to elementary school or from middle school to high school, Aaron has developed a system to help ease the adjustment period.

First, she observes children in their current environment and develops mini-profiles of their needs, strengths and challenges. Next, she prepares both child and new teacher for the move. "I have the prospective teacher come and observe and meet the child in his or her environment," says Aaron. "I might tell the child a social story about things that happen at his new school."

Aaron usually suggests that children first visit the new classroom after school hours, when the room is quiet and they can explore it without distraction. Then she plans a visit during school hours. Sometimes Aaron compiles a book with photographs taken at the new school, featuring the child on the stairs, in the classroom and in the cafeteria. And depending on the child's level of understanding, she sometimes gives the new school the big build up. "I talk to them about being big kids and being ready to go to this great school," she says.

"Children at high risk of having a great deal of difficulty adjusting to a new placement might need to be very slowly and gradually integrated into the school," says Aaron. She has occasionally advised temporarily setting up a child in an extra classroom, and then very gradual inclusion into school activities.

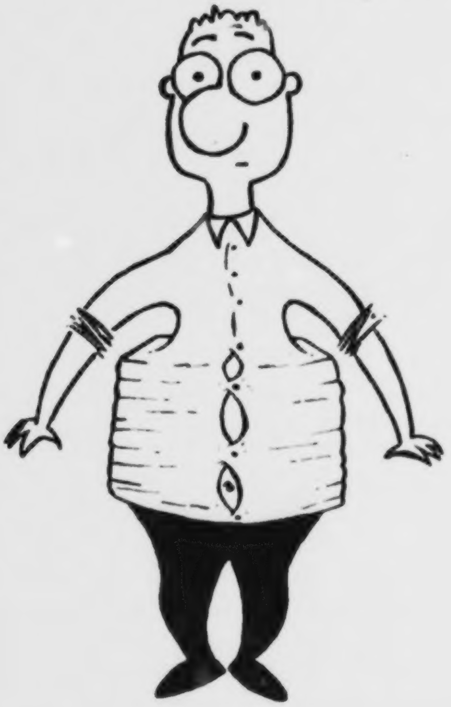
The unhappiest of all transitions comes because of physical or verbal abuse in a classroom or treatment center. "It doesn't happen often, but I've seen teachers who were abusive, and I've reported them," says Aaron.

continued on page 98

This series is made possible by an unrestricted educational grant from the International Family Institute at The Center for Discovery in Harris, New York. www.discoveryifi.org - www.thecenterfordiscovery.org

960

As our volunteer clearly demonstrates, 21* pediatric medical journals can be quite difficult to digest.



In fact, unless you have a medical degree we wouldn't recommend it.

If you have an interest in the latest breakthroughs and research published in pediatric journals, but don't have the medical training required to easily digest the information, there is an alternative.

ChildHealthMonitor.org publishes articles adapted from the latest monthly issue of each of the world's leading pediatric publications*. The information is the same. The difference is that much of the medical jargon is replaced with everyday language. It's also online which means that anyone with an Internet connection can now have instant access to reliable, useful information on the latest advances in treatment, prevention, and caring for kids.

Simply, visit **www.childhealthmonitor.org** and you too can have unlimited access to hundreds of simply written articles on up-to-the-minute pediatric discoveries.

We think you'll find this option much more palatable. (Our volunteer did.)

* Acta Paediatrica, Archives of Disease in Childhood, Archives of Pediatrics and Adolescent Medicine, Brain and Development, British Medical Journal, Child: Health, Care and Development, Developmental Medicine and Child Neurology, European Journal of Pediatrics, Journal of Adolescent Health, Journal of Child Psychology and Psychiatry, Journal of Paediatrics and Child Health, Journal of Pediatric Psychology, Journal of Pediatric Surgery, Journal of Pediatrics, Journal of the American Academy of Child and Adolescent Psychiatry, Journal of the American Medical Association, The Lancet, New England Journal of Medicine, Pediatric Infectious Diseases Journal, Pediatrics, and Research in Developmental Disabilities

CHM

ChildHealthMonitor.org

continued from page 96

In some cases parents aren't satisfied with any of the options available to them and decide to home school their children. Conversely, some parents come to the decision that residential treatment is in the best interest of their child.

Residential treatment is often considered when a child, with or without behavior problems, has multiple disabilities difficult to address adequately in a day-school setting. "A few parents choose residential treatment after their children become dangerously aggressive and destructive," says Aaron. Their child is no longer learning or making progress in school. "In the end, some kids are more successful when they have the full-time services they need for educational, recreational, behavioral and medical support. Controls available in residential treatment, along with constant evaluation, help the child learn," Aaron says.

> **One hard thing for parents when children leave early intervention is that the emphasis is no longer on the family, but only on the child. There's the change from the IFSP to IEP (Individualized Education Plan).**

Transition teams consisting of educational and medical specialists now realize that integration with regular education students just isn't feasible in every situation, says Tammy Walkup, a speech-language pathologist and member of an Oregon school district transition team. "We now have two specialized classrooms for children with autism. We've had to agree that sometimes these children make better progress being taught by people specializing in certain techniques, such as applied behavior analysis (ABA). And the kids are making progress."

Walkup's transition team functions similarly to one she worked for in Nebraska. The team includes Walkup, an occupational therapist, school psychologist, a nurse and other specialists, depending on each child's disability.

"We conduct evaluations for children who are three to four years old to determine whether they're eligible for special education. Then we come in later when it's time to transition from preschool to elementary school. A year before kids transfer to elementary school, we start talking about the upcoming transition. We make sure the parents know what the steps will be. We have a meeting at the winter Individualized Family Service Program (IFSP) review, and parents receive a transition manual outlining the entire process. The team suggests possible sites, and the parent, along with someone from the team, visits the various classrooms."

Typical alternatives for children with cognitive disabilities, for example, include regional learning centers, life skills or special education classrooms, and part- or full-time integration in a regular classroom. Sometimes these alternatives are not adequate and special non-public schools in residential programs must be considered.

"The team makes a recommendation and we iron out any differences of opinion with parents and other members of the team," explains Walkup. "One hard thing for parents when children leave early intervention is that the emphasis is no longer on the family, but only on the child. There's the change from the IFSP to IEP (Individualized Education Plan). Also, their children were usually involved in primarily play-based activities, and now the focus is far more academic."

Walkup admits that the transition process is sometimes a struggle, but estimates only about ten percent of parents have serious disagreements with the team on placement, and that just a few of these proceed into due process and mediation. "It's been my experience that our team is seen in a positive light, and I'm very proud of that," she states.

My 8-year-old son Jalen, diagnosed with autism and mental retardation, has already journeyed through a variety of transitions. After he was first identified at age two as developmentally delayed, services consisted of a monthly visit from an early intervention case manager. She came over to play with Jalen and suggest techniques to help him develop his language and fine motor skills.

The easygoing nature of intervention changed drastically when Jalen turned three and officially became "preschool age." He was formally diagnosed with autism and retardation. The case manager insisted that he needed to be in a community preschool, so one was found and an aide was assigned to him. But it was clear that he didn't relate to the other children, and the teachers were finding it difficult to include him successfully despite consultations with the case manager. Jalen responded well to his aide, though, and I proposed he start a home-based program.

After much resistance, the idea was approved and preschool was brought home to Jalen. Aides spent three hours with him each day, implementing the individualized program his case manager and I designed. He also received speech therapy and occupational therapy services at home.

After a year and a half with the home program, I felt he was ready to transition to a local specialized preschool comprised of both typically developing children and children with austism. At first, adjustment was difficult, and I was severely shaken each morning as I dragged him, kicking and screaming, onto the bus. Once at school, he cried and refused to join circle time and various other activities. But with the help of a patient teacher, he calmed down in a matter of weeks and started to enjoy his new class.

Two years later a new applied behavior analysis (ABA) classroom for kids with autism opened, the only public institution of its kind in the area. The timing was perfect; it was just as Jalen was leaving the preschool program. Jalen was lucky enough to be one of the kids recommended for the program. It was a half-day program with ten children, one teacher, and ten assistants, to allow lots of one-on-one as well as group activities.

The children were to go to their neighborhood schools in the afternoon. Jalen was assigned to an afternoon life skills classroom housed in an elementary school across town because he wasn't able to understand basic kindergarten academics. There he was sometimes mainstreamed for phys ed, recess and other activities.

Initially, Jalen learned a lot from the ABA program. However, the long bus rides, high teacher turnover rate and other problems eventually made this placement unsatisfactory. Recently I suggested that he stop attending the morning class altogether and attend the special education classroom full-time. That is his placement now, and it seems to be working well.

Unfortunately, Laura Yoder did not experience such a seamless transition. Her son Matthew, six and a half years old, has Down syndrome, and Laura recites a litany of frustrations in getting what she considers an appropriate education for him. She points to her son's preschool class as the first link in a broken chain that led to problems when it was time to transition to public school. "I felt that they didn't deal with his refusal behaviors well," says Laura. "They let him get away with not working as hard as he could, so he didn't develop to his full capacity during that crucial time. That, in turn, affected his options when it was time to transition to kindergarten."

"During the entire transition process I felt overwhelmed, powerless, confused, and inadequate as my son's advocate," Laura said. She also felt that the time and energy spent advocating for her son took away from the time she spent with him.

Laura, a former public school music teacher, was familiar with the school environment and savvy about various programs offered. She decided against a particular life skills classroom because several students there had severe behavior problems, and she feared they would be negative role models for her son. She was offered an "extended resource" classroom for children who need lots of academic support, an academic step above the life skills program. But that placement didn't seem to fit either.

Laura describes working with Matthew's IEP team as particularly challenging, and this impression was later confirmed by a professional advocate. "The people on the team were nice, but when it came to my son's academics we could not work together." After doing her own research, she asked that he be included in several programs that the team decided against. "After the advocate started coming to meetings with me, she agreed the team was unusually resistant to compromise," says Laura.

"During the entire transition process I felt overwhelmed, powerless, confused, and inadequate as my son's advocate," Laura said. She also felt that the time and energy spent advocating for her son took away from the time she spent with him. She struggled with feelings of anger and disappointment, of betrayal, and of not being understood. "I felt they had no faith in Matthew's abilities, and that my input was disregarded. The experts think they're right, but parents know their children more than anyone else." Finally, against her better judgment, Laura agreed to another life skills classroom in the afternoon following mainstreamed morning kindergarten with an aide. She experienced much difficulty with the life skills teacher. "We just didn't agree," she says.

She requested an out-of-district transfer to a nearby city, and is still waiting for a final decision. In the meantime, Laura decided to hire a

continued on page 100

continued from page 99

tutor for her son using direct instruction. "He's doing well now," she reports. She feels he's moving in the right direction at last. To help with this process, Laura recommends the book, "The Complete IEP Guide: How to Advocate for Your Special Education Child" (available from the EP Library, http://www.eplibrary.com).

Sometimes a transition to the right placement is a positive, life-changing experience for the entire family. Mary Jo Reich and her husband David, both New Jersey attorneys, have found the road to appropriate services far easier than expected.

Their son Scott, now 13, has a metabolic disorder called Mucolipidosis IV, or MLA for short. "It's extremely rare. It's in the same family of such Jewish metabolic storage diseases as Tay-Sachs, but children don't die from it. Instead, they have profound disabilities," she explains. Scott cannot walk or talk, and has severely impaired vision.

"He understands and communicates with modified sign language, waves and says 'Mama'," Mary Jo says proudly. "He also loves to go to restaurants—he shows he wants to go by waving bye-bye and making the sign for eat. He also loves music and poetry; blasting Bruce Springstein in his CD player always makes him laugh."

But two years ago, Scott wasn't so happy. "He was growing out of his old school," says Mary Jo. "It was a good school, but they couldn't really help him any longer. He wasn't progressing, and he was no longer happy there. Everyone agreed he needed a change."

So it was back to the IEP team and on with the search for a new placement. After visiting all the recommended schools, the couple felt there were no safe, certified schools for children in New Jersey with multiple disabilities, cognitive deficits and visual impairments.

Then Mary Jo and Dave discovered New York's Center for Discovery in Harris, NY. Friends had placed their own child at this residential school and were very happy with it. The Reichs visited and were immediately impressed. "It is such a beautiful place, and the people there are wonderful. We were just blown away," raves Mary Jo.

However, getting approval for Scott to attend the school was complicated because the school had never admitted an out-of-state student and wasn't certified in New Jersey. The school submitted the proper paperwork with the Reichs' help, and it was soon certified by the Department of Education and other agencies in New Jersey.

continued on page 102

Resources

Education Law

Parent Advocacy Coalition for Educational Rights Center (PACER)
(952) 838-9000; PACER Parent Training and Information Centers
(888) 248-0822;
http://www.taalliance.org ; e-mail: alliance@taalliance.org
Assistance and materials for parents and professionals in securing a free and public education for all children.

Wrightslaw
(877) 529-4332;
http://www.wrightslaw.com; e-mail: webmaster@wrightslaw.com
A free web site offering extensive legal information about rights and protections regarding special education, and a source for ordering the books From Emotions to Advocacy-The Special Education Survival Guide and Special Education Law

Healthcare coverage

Family Voices
(888) 835-5669;
http://www.familyvoices.org ; e-mail: kidshealth@family voices.org
Family Voices is a national grassroots organization. Coordinators in each state provide information on SSI (Supplemental Security Income), Medicaid, and how to appeal insurance claims.

Families USA
(202)628-3030;
http://www.familiesusa.org e-mail: info@familiesusa.org
A not-for-profit organization dedicated to high-quality, affordable health care and long- term care.

National Information Center for Children and Youth with Disabilities (NICHCY)
(800) 695-0285;
http://www.nichcy.org
Provides free information on a wide variety of disabilities and helps to identify educational programs and services.

Emotional Support

Beach Center on Families and Disability
(785) 864-7600;
http://www.beachcenter.org e-mail: beach@dole.lsi.ukans.edu
Distributes family-friendly products including manuals, booklets and videotapes. Web site links to statewide Parent-to-Parent organizations that match parents seeking information and support with experienced parents of children with similar disabilities.

The Center for Discovery
Box 840 - Benmosche Road Harris, New York 12742
(845) 794-1400
http://www.thecenterfordiscovery.org
http://www.discoveryifi.org
A private, not-for-profit prep school that provides educational, clinical and residential programs and comprehensive on-site evaluations for children and adults with significant disabilities. The International Family Institute offers information, assistance and support to educational professionals and families of children with disabilities.

BEST COPY AVAILABLE

www.abilitiesexpo.com

EXPO

Chicago Metro
Donald E. Stephens
Convention Center
August 16-18

New England
Bayside Expo Center
September 20-22

Northern California
San Mateo County
Expo Center
November 22-24

Education and *Equipment* to *Empower.*

Come **sample products** and **talk one-on-one** with service providers. As our guest you can attend **complimentary educational workshops** on everything from better sex to better jobs. Or perhaps you would like to see the power of new technologies in our **Access Ability Pavilion**. There are many options for you at **Abilities Expo**.

For more information please call (800) 385-3085 or (218) 723-9130 outside of the USA.
www.abilitiesexpo.com

BEST COPY AVAILABLE

abilities EXPO

PRESENT THIS COUPON FOR FREE ADMISSION

[ADMIT ONE]

Bring coupon to any **2002 Abilities Expo** and save the $5 on-site registration fee.
Coupon must be filled out to be valid and may be photocopied for additional registrants.

NAME: ____________________

ADDRESS: ____________________

CITY: ____________ STATE: ____ ZIP: ________

For information call:
(800) 385-3085
(218) 723-9130 (outside USA)

Produced and Managed by:
ADVANSTAR COMMUNICATIONS

♿ All events are wheelchair accessible.

© 2002 Advanstar Communications Inc. All rights reserved.

Circle #17 or visit www.eparent.com/adinfo

985

continued from page 100

While mulling over the decision to enroll him at Center for Discovery, the Reichs talked to another couple who'd recently enrolled their own son, a boy in his late teens. "We asked them if they had any regrets and they said their only regret was that they didn't enroll him sooner, because his life was better there."

Convincing the IEP team and the school district to approve the placement and foot the bill was surprisingly easy, says Mary Jo. "They told us they wanted what was best for Scott and after visiting, they agreed that the Center for Discovery was best. There are only eighty children with Scott's disease in the world, and ten of them reside at Center for Discovery."

"It's been my experience that it doesn't help to approach the schools as if they're your enemy," Mary Jo notes. "Early after Scott's diagnosis, I went to meetings for parents of children with special needs and there was a lot of emphasis on demanding what you wanted for your child. But later I found that the people in the field are caring, reasonable people who can't be described as the enemy."

At the Center for Discovery, students receive speech, physical and occupational therapy, and enjoy a therapeutic pool, horseback riding, music, animals and nature. Scott lives in a brand new house for out-of-state children and visits the other children's houses for various activities, goes out on field trips and socializes extensively. During the winter, the Reichs drive nearly two hours to visit him at the center. During the warmer months, they bring him home for weekends and vacations.

"It's just an amazing place. Scott loves it. When we go there and he sees us, he doesn't burst into tears like he did those last years at the old school. He used to cry because he was anticipating us leaving again. Now he gives us a hug and kiss and is happy to see us, but he's also happy to come back to the center," says Mary Jo. "Everyone there is well-trained, and he works with therapists all the time. There is 24-hour coverage. There's always guidance, education and supervision. This is the least restrictive setting for Scott. This is where he needs to be. We feel very, very lucky."

Another major transition occurs when children leave high school and enter the world of adults. Outside of the comfortable nest of public school services, parents and young adult children may find themselves bewildered — and without the support they need.

In accordance with IDEA, transition plans for adulthood and a life after school are mandated to begin when a child is fourteen. Students are typically taught self-management skills such as money management, cooking and laundry. By sixteen, future plans should be narrowed down.

There are myriad avenues of possible support, such as community-based waged work, vocational rehabilitation, sheltered work programs, social security benefits and public assistance funding. But accessing these supports is sometimes difficult; parents may need the assistance of an advocate or a case manager.

Some former special education students require only minimal support to live on their own, such as visits from caseworkers to help with specialized tasks. Others stay at home with their parents. Many states are beginning to develop support programs, such as respite care and recreational opportunities, for adult children living with their parents. Many communities have group homes for adult children with extensive needs whose families want to place their child outside the home, but may face long waiting lists for placements. Experts suggest getting children's names on group home waiting lists years before they leave high school, and helping their children set realistic goals for the future.

Jeffrey and Eva Kittay's daughter Sesha was 32 when she enrolled at the Center for Discovery's adult residential program three years ago. Sesha has multiple disabilities including profound retardation, cerebral palsy and scoliosis, and is semi-ambulatory. Although the Kittays did some searching for an appropriate placement when she aged out of public school services at age 21, they were disappointed in the quality of services they found. For a while she attended a day program but "not much attention was paid to the kids, and we kept her more and more at home," says Jeffrey.

Finally Sesha left the day program altogether and the Kittays hired therapists and aides to care for her at home. They found the Center for Discovery "none too soon" says Jeffrey, as it was becoming harder to care for Sesha at home, particularly after a long-term caregiver needed to retire. "She's much happier now. She's becoming stimulated and has friends. She's enjoying all the people around her."

Ultimately, the success of parents and the success of school programs must rest on programs' abilities to move children and young people toward maximizing their potential. There are no "do-overs" because at 21 entitlement to an appropriate educational program ends. Finding the program that will best serve your child and making the necessary transition is essential at each level of education. EP

Cynthia Whitfield is a free-lance writer with four children. She has written articles for her local newspaper, for an advocacy newsletter for people with disabilities and for a career exploration magazine. She spends most of her time at home writing, running a home-based preschool and homeschooling her son Logan, who has autism.

Parents Criticize Special Ed in Schools

According to a recent survey of parental opinion, many parents of special needs children believe that personnel are qualified to deal with their children, but school systems do not offer special help unless parents insist.

The Public Agenda poll of 510 parents of children in special education also found:

- 1 in 6 parents have sued or threatened to sue their child's school district to get proper services
- 55% of parents must research themselves to find what help is available to them
- 45% say their child's school program doesn't adequately prepare students for the real world, and
- 35% become frustrated when it comes to finding the services they need.

For information on Public Agenda or a copy of the survey, visit their web site at http://www.publicagenda.org.

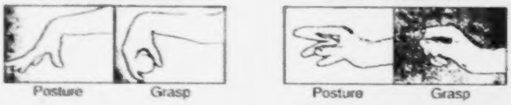
FIRSTFlex™

improving reach, grasp and pinch together.

Caring For Life

FIRSTFlex™, for children with spastic hemiplegia, combines patented bracing with electrical stimulation.

Before Treatment **After Treatment**



www.ultraflexsystems.com

Call 1-800-220-6670 for free video and research studies.

Circle #61 or visit www.eparent.com/adinfo

PERSONAL INDEPENDENCE

THE EVERGREEN CENTER prepares students to lead meaningful lives in the community. Through an individual educational program combining basic skills and behavior development,our students learn to lead more independent lives as integrated members in the community.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631
Serving students with developmental, medical and behavioral needs since 1981.

Circle #33 or visit www.eparent.com/adinfo

Camphill Special School
Children's Village
A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- **Pennsylvania Approved Private School**
- **Waldorf Curriculum (Member of AWSNA)**
- **Both Day & Residential Programs Available**

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236
www.BeaverRun.org

Circle #23 or visit www.eparent.com/adinfo

new products

THE GUN LAKE ADVENTURE SERIES

The Barn at Gun Lake
Mystery Explosion!
Blackbird Island
Noonday Trail

The Gun Lake Adventure Series, by author Johnnie Tuitel, depicts the life and adventures of twelve-year-old Johnnie Jacobson. Jacobson, who has cerebral palsy, leads his friends on several mystery-solving adventures from his wheelchair. The main character is based on Tuitel's own experiences growing up with cerebral palsy. The adventure series includes The Barn at Gun Lake, Mystery Explosion, Black Bird Island, and Noonday Trial. These four books are great examples in teaching children how to overcome adversity. The Gun Lake Adventure Series can also assist parents and teachers in opening up discussions on diversity and how to treat people with disabilities.

Cedar Tree Publishing, 2455 Norcrest Drive, Norton Shores, MI 49441-4450, 888-302-7463
Web site: http://www.tapshoe.com

LECKEY™ EASY SEAT

The Leckey™ Easy Seat is a positioning chair designed to provide a variety of customized seating options. This height-adjustable chair features seat depth, lower leg and backrest height and angle adjustments. The adjustable armrest allows for tray positioning. The adjustable legs can create a tilt-in-space effect. The positioning seat comes with side pads and a hip belt. Optional accessories include a footplate with foot straps, flexible lateral supports, pommel, tray, high back with head laterals and casters. The Leckey™ Easy Seat is available in four sizes from nursery to school aged children.

Sammons Preston, 4 Sammons Court, Bolingbrook, IL 60440, 800-323-5547, 800-547-4333 (fax),
E-mail: sp@sammonspreston.com, Web site: http://www.sammonspreston.com

VOCAFLEX™

VocaFlex™ is an augmentative and alternative communication device with a recording capacity of one hour. It comes with ninety bar-code identifying overlays and stores fifty-one overlays at once. Other features include nine Finger Guides, a three-position volume switch, message lengths of ten and twenty seconds and automatic on and off.

Saltillo Corporation, 2143 TR112, Millersburg, OH 44654, 800-382-8622, 330-674-6722, 330-674-6726
(fax), E-mail: aac@saltillo.com, Web site: http://www.saltillo.com

PLEXTALK™

PlexTalk™ is a portable digital recorder with a recording capacity of fifty hours. This digital talking book also plays back and records music in CD (CD-DA), MP3 and Daisy 2.0/2.02 format. The PlexTalk™ features resume play, audio skip protection and an on and off timer. It also comes with a rechargeable lithium ion battery, Flash ROM upgrade and a built in USB port. Voice guidance and the design of the unit assists users with vision and learning disabilities.

PLEXTOR™ Plextor, Corp., 48383 Fremont Bulevard, Suite 120, Fremont, CA 94538-6509, 510-440-2000,
510-651-9755 (fax), E-mail: info@plextalk.org, Web site: http://www.plextalk.org

---

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

EXCEPTIONAL PARENT
2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/handling). To order, call 1-800-535-1910.

Circle #1

EYEGAZE COMMUNICATION SYSTEM

Lets your child communicate using only his eyes!

Eye controlled speech synthesis, environmental controls and PC/computer access

Now It's Portable!

800-393-4293 www.eyegaze.com

LC Technologies, Inc., Fairfax, Virginia

Circle #2

freedom

what is your definition?

call us today!

1.800.661.9915
www.freedomconcepts.com

Circle #3

EXCEPTIONAL PARENT

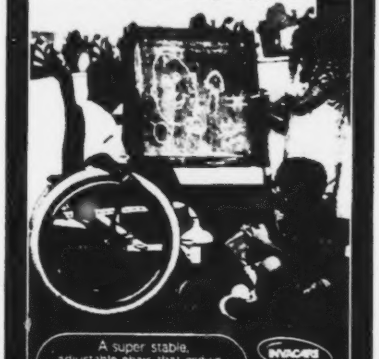
Catch Exceptional Parent at Newsstands Near You

Find it. Buy it in bookstores all across America, every month. Exceptional Parent magazine is sold every month in Barnes & Noble Superstores, Borders, Crown, Encore Stores, Hastings, Lauriats & Tower Books. $4.95 Cover Price.

Circle #4

INTRODUCING

the Invacare® Top End® Terminator® Jr. for kids who are going places!



A super stable, adjustable chair that grows—and that kids can move all by themselves

INVACARE
Yes, you can.

Circle #5

Natural Access™

Expand your horizons with the Landeez All-Terrain Wheelchair!

Rolls easily over sand, snow, gravel, and uneven terrain, so you can enjoy the outdoors

969

For more info 800-411-7789 or visit www.landeez.com

Circle #6

MARKETPLACE

ACCESSIBLE TRAVEL

Disney Area Villa rentals
4 miles from Disney World. 3/2
(sleeps 8) Accessible Resort Villa.
All your Special Needs, Scooters,
Oxygen, Cruises & Dialysis
Program by www.medicaltravel.org
Call 1-800-778-7953.

ATTORNEY

Attorney Richard Gottesman
(800)295-1107
gottesman@law.com
Cerebral Palsy, Brachial Plexus/Erb's
Palsy and Childbirth Injuries

BEACH WHEELCHAIR

The Features Make All the Difference

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials
and tools specializing in products used
for Applied Behavioral Analysis;
flash cards and manuals.
Website: http://www.difflearn.com

EQUIPMENT DEALERS

American
Discount Medical
Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands—Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider.
Resource information:
www.medmarket.com
e-mail: info@archhp.com

Ask about our Youth Brief sample pack. Only $5.99!

HDIS

FREE CATALOG

Call Today!
1-800-2MY-HOME™
(1-800-269-4663)

FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg,
PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

BEACH SWIMMING POOL

TIRALO™
FLOATING BEACH CHAIR

Call now: (360) 796-3197

www.oasisllc.com

MONITORING SYSTEM

Care Electronics Inc.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price.
Call for FREE CATALOG

SEATING & POSITIONING

Designed With Children In Mind
Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Leckey products feature lighter mobile bases, more adjustable components, peer level positioning, child friendly positioning straps and playful colors.

- Freestander
- Totstander
- Easy Seat
- Advance Bath Chair
- Toilet/Shower Chair
- Basic Bath Support
- Pronestander

Call Sammons Preston today at 1-800-323-5547 for a complete Leckey® brochure.

TOYS AND HOBBIES

TFH (USA) LTD
4537 Gibsonia Rd.
Gibsonia, PA 15044
800-467-6222
www.tfhusa.com
e-mail: info@tfhusa.com
Fun products for recreation and education of special needs children.
Request a FREE catalog.

VAN CONVERSION DEALERS

MASSACHUSETTS

Motion Automotive Specialty
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—
Day, Week or Month.

Send us your Adapted Halloween Costumes Ideas!

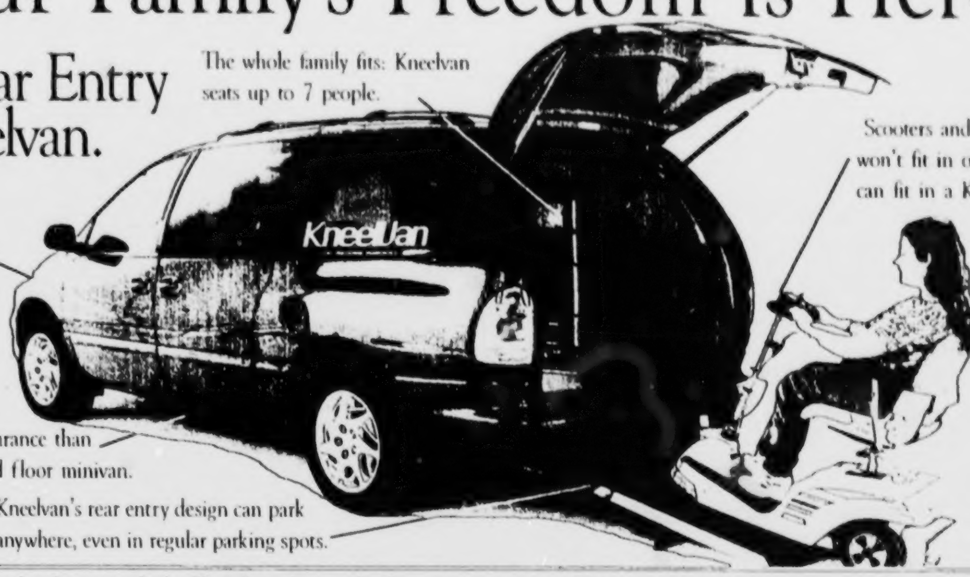
EP is looking for submissions for our annual Halloween Costume column. Please send your photos with costume instructions to:

Exceptional Parent
Attn: Halloween Costumes
65 East Route 4
River Edge, NJ 07661

070

Your Family's Freedom is Here:

The Rear Entry Kneelvan.



The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel.** Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #36 or visit www.eparent.com/adinfo

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:

1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy
For Editor-in-Chief statement see our Contents page

TO ADVERTISE IN MARKETPLACE CONTACT:

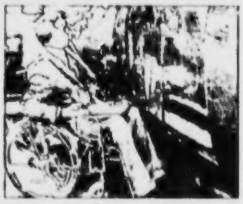
Barbara Nastro

TEL: (908) 534-6366

FAX: (908) 534-6941

DRIVE-MASTER

50 YEARS of Providing Mobility for the Physically Challenged



STEERING YOU IN THE RIGHT DIRECTION

Innovators Then...

Partial Features Include...

- Hand Controls
- Reduced Effort Steering
- Reduced Effort Braking
- Foot Steering
- Left Foot Gas Pedals
- Wheelchair Lifts
- Porch Lifts
- Steering Devices
- Backup Brakes & Steering
- Horizontal Steering
- Complete Van Conversions
- Block Pedal Extensions

And Much More!
For additional info.
contact Drive-Master

Experts NOW!

DRIVE MASTER

9 Spielman Road, Fairfield, NJ 07004-3403
Phone: (973) 808-9709 • Fax: (973) 808-9713
E-mail: drivemaster@drivemaster.net
Web: www.drivemaster.net

24 TURNAROUND SERVICE

Circle #20 or visit www.eparent.com/adinfo

Our Little Angel

by Alycia and Gina Crilly

Our little sister Mary is three years old and has a rare genetic disorder called Joubert syndrome. She has a tracheostomy and is ventilator-dependent. She cannot walk, talk or eat by herself. Her liver disorder also makes it hard for her to function. Despite these problems, Mary is the happiest person we know.

Even though Mary has all these difficulties, she has managed to come a long way. By the use of switches, Mary can tell us things. She has also learned a few commands. If you put a stick in her hand and say, "Mary, show stick," she will proudly raise it up to you with a huge smile on her face. If you ask her "Where's your feet?" she raises her feet into the air, waiting for our response. She will gladly give you a high five, and will give you a lovable hug if you ask for it.

Mary is an extremely happy child. Almost every day, we make sure she goes on her walk. Whether to a park or just around the neighborhood, Mary simply enjoys relaxing and being with her family. She has also shown interest in particular things. For example, the folk singer Raffi is one of her favorites. His songs calm her when she is having a bad day and always leave a smile on her face. She has all of his CDs, some books, videotapes and even a shirt! In addition to Raffi, Mary is interested in books, music, light up toys, balloons and glow sticks. Her unique personality is loved by everybody who meets her.

We are so proud of our little sister and enjoy her every day. We are never embarrassed by her and answer all questions that others may ask about her disability. When we feel blue, we like to be near her. Seeing that we feel down, Mary gives us a huge smile from ear to ear. Her brilliant blue eyes sparkle when she looks at you and her charming personality is bound to cheer up anybody's day.

We believe that Mary teaches people to appreciate every day and to enjoy the simple things in life. We have no doubt in our minds that Mary was put on earth for a very special reason. People notice that despite her disabilities, she is one of the happiest children around. We were blessed with an angel who was touched by God. EP

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number and e-mail address! ***Now on the Web!*** We now include **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

972

BEST COPY AVAILABLE

They Have A Lot to Say...

and you can be the one to help them say it.

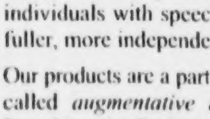
Since 1983, DynaVox Systems has been committed to helping individuals with speech, language and learning disabilities to lead fuller, more independent lives.

Our products are a part of a broad group of communication methods called *augmentative and alternative communication,* or AAC. DynaVox AAC devices help thousands of young people with speech disabilities due to cerebral palsy, autism, mental retardation and Down's syndrome to express themselves.

As the AAC industry leader, our success is based on a strong partnership with our customers. Our foremost objective is to ensure that our customers receive the best solutions to meet their immediate and long-term communication needs. This is enhanced by a comprehensive network of support services including:

- ***Funding Assistance***
- ***Product Training and Support***
- ***Expert Field Support***
- ***Telephone Customer Support***

All DynaVox associates are committed to the development of innovative services. Together we can achieve our goal as we continue to improve the lives of individuals with speech disabilities by bringing them the power of communication.

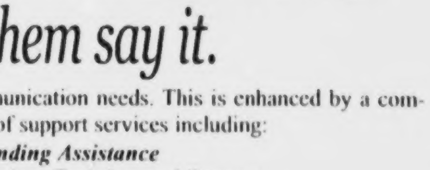


FREE!

DynaGuide Training CD included with the purchase of a DynaVox 3100, DynaMyte 3100 or Dynawrite.

KNOWLEDGE BASE
24/7
On-line Tech Support

Visit our 24/7 On-line tech support at www.dynavoxsys.com!



DYNAVOX
a division of SUNRISE MEDICAL
InTouch with Communication Solutions for Life.

For more information please contact our inside sales department at:
1-888-697-7332
www.dynavoxsys.com

Circle #30 or visit www.eparent.com/adinfo

A Better Bedtime Story

The Vail Enclosed Bed

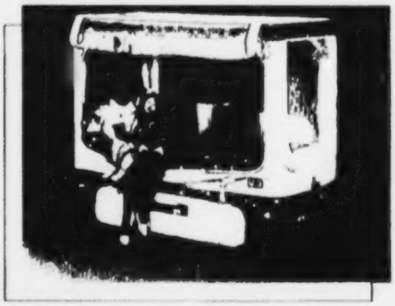
Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for your child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt. Plus, we provide assistance in obtaining insurance approval.

Available from home health-care products dealers, or direct from the manufacturer.

For a FREE catalog, call:
1-800-235-VAIL



Ask about Our Decorator Accessories.

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

Sheri Wittmer
Sandusky, Ohio

Vail Meadows Therapeutic Riding Center

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for challenged riders.

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

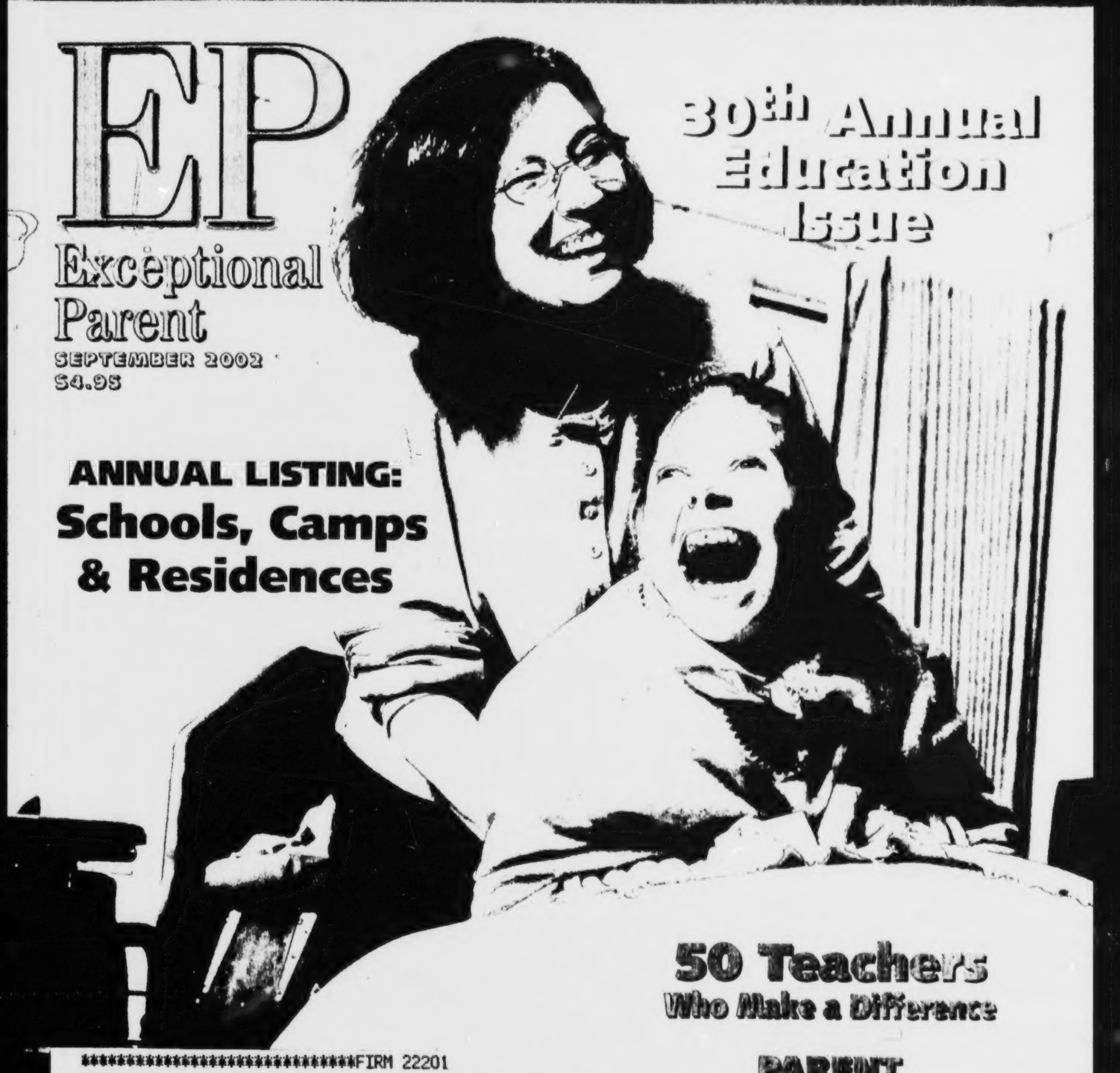
VISA MasterCard

Circle #62 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent

SEPTEMBER 2002
$4.95



30th Annual Education Issue

ANNUAL LISTING: Schools, Camps & Residences

50 Teachers Who Make a Difference

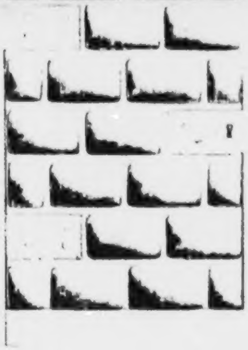
PARENT EMPOWERMENT: Final Installment

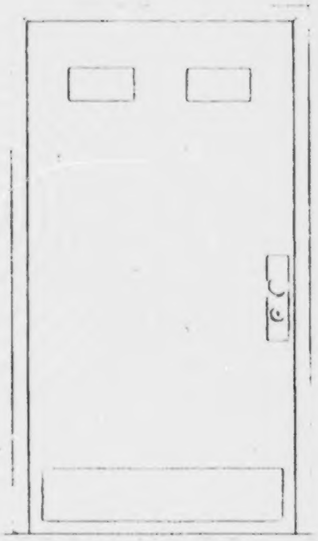
*******************************FIRM 22201
22201AQU111CU00 ZNI02
ACQUISITIONS
ERIC CLEARINGHOUSE
COUNCIL FOR EXCEPT R= 6925
1110 N GLEBE RD STE 300 S112 P3
ARLINGTON VA 22201-4795

www.eparent.com

975

BEST COPY AVAILABLE





We open doors to bring out human potential and create productive lives.

The New England Center for Children uses principles of Applied Behavior Analysis and educational programs to turn

uncommunicative into communicative...

misbehavior into behavior...

disorder into order...

disability into ability...

dysfunctional into functional...

uneducated into educated...

disconnected into connected...

incapable into capable.

Programs for children with autism

The New England Center
FOR CHILDREN
We Open Doors

33 Turnpike Road • Southborough, Massachusetts 01772-2108
508.481.1015 Fax 508.485.3421
www.**necc**.org

Circle #68 or visit www.eparent.com/adinfo

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

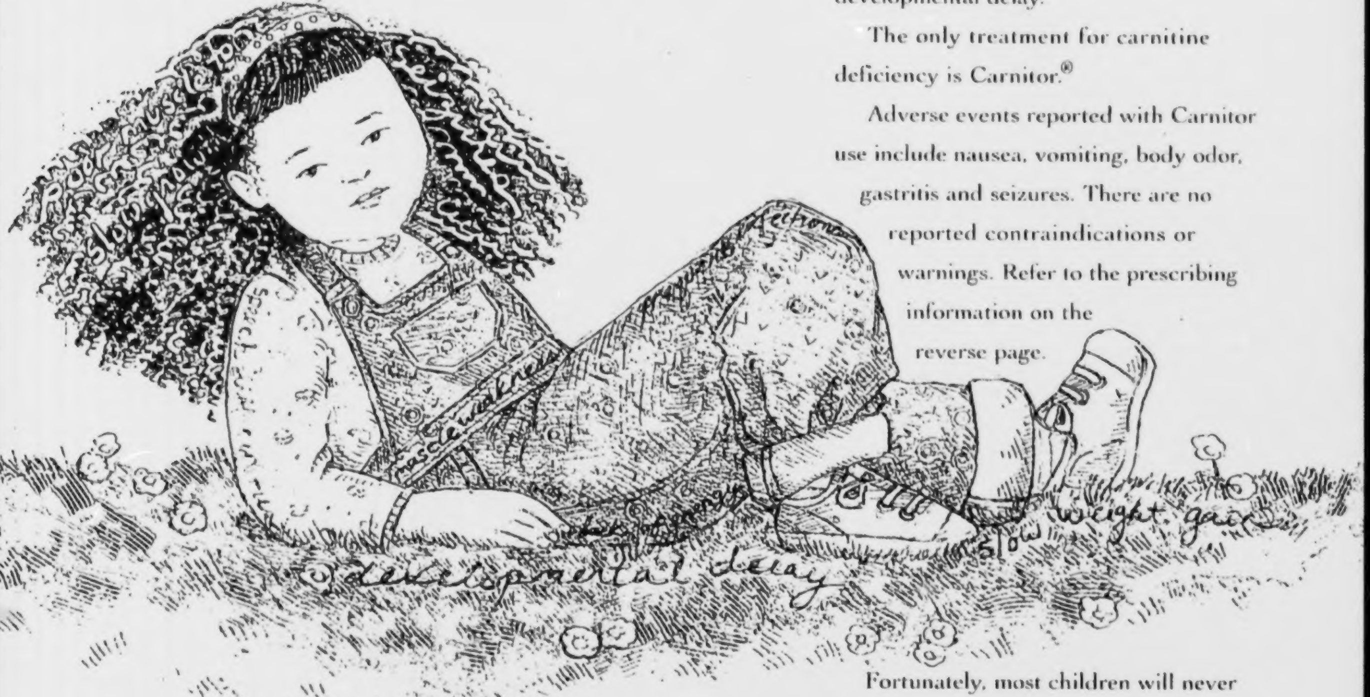
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

EP

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Circle #77 or visit www.eparent.com/adinfo

CARNITOR®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

Imagine...

if all of your other
choices could be this simple

MOTOR COMPANY INC LIBERTY

Introducing a
**zero
maintenance**
conversion van with wheelchair access

Starting Under
$20,000 US
(Including vehicle and modification)

- 1996-2002 Windstar Models Available
  (All vans come with brand new conversions)
- Professionally trained staff ready to help you
- The rear-entry design provides for the safest and most reliable wheelchair accessible minivan on the market.
- The Liberty Motor Co modified Ford Windstar looks and drives like a standard minivan, offering a quiet, comfortable ride.
- Money Back Guarantee

BEST COPY AVAILABLE

Circle #59 or visit www.eparent.com/adinfo

1 (888) 578-8886 www.libertymotorco.com

contents

SEPTEMBER 2002 ◦ VOLUME 32, ISSUE 9

Education 2002

25 Teachers and Special Ed
By Maria Tortoreto
EP honors some of the nation's finest teachers for their work with children with special needs.

32 Twins Transition
By Laura Apel
Alba and Anastasia Somoza are heading to college and are already thriving in their new environments.

36 College Bound
By Carolyn Cantu
A look at two different colleges exclusively for students with disabilities.

40 Ridgeway School: A Very Special School
EP Magazine's Educational Institute of the Year.

42 Enhancing Inclusion with the Navy Run, Jump 'n' Throw
By Joseph Valenzano, Jr. and Jim Santos
The Navy Run, Jump 'n' Throw program offers participation in track and field events.

48 How to Find a High-Quality Inclusive Child Care Program
By Stacy Scott, M.Ed. and R.A. McWilliam, Ph.D.
Ideas for how parents can help with the inclusion process.

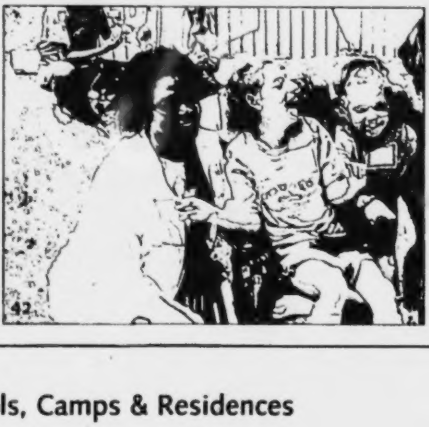
52 A Test of Faith: College Testing Services Will Stop Flagging Scores
By Julia Steele
The College Board and ACT will no longer denote scores achieved under special conditions.

56 DD-SNAP
By J. Michael Hennike
A new assessment tool that parents and families can learn to use.

58 Parent Perspective: Homeschooling
Parents tell why they choose to homeschool their children with disabilities.

62 401 Kid
Parents now have better ways to save for college under new tax laws.

64 The Paraeducator Paradox
By Patricia H. Mueller, Ed.D.
A look at the paraeducator profession.



FEATURES

68 Toolbox of Hope
A workbook to help children learn to come to terms with their illnesses.

80 Steroid Use in the Neonatal Intensive Care Unit: A Preventable Cause of Cerebral Palsy and Developmental Delay
By Andrew Unger, MD
Doctors now caution that dexamethazone, a steroid commonly used in NICUs, can increase the risk of developmental delays.

SPECIAL REPORT: COVER STORY

72 Informing, Empowering and Keeping Parents Involved: A Four Part Series
By Susan Carucio Colacello
Part IV: Family Wellness, Quality of Life and the Long View

SPECIAL REPORT:

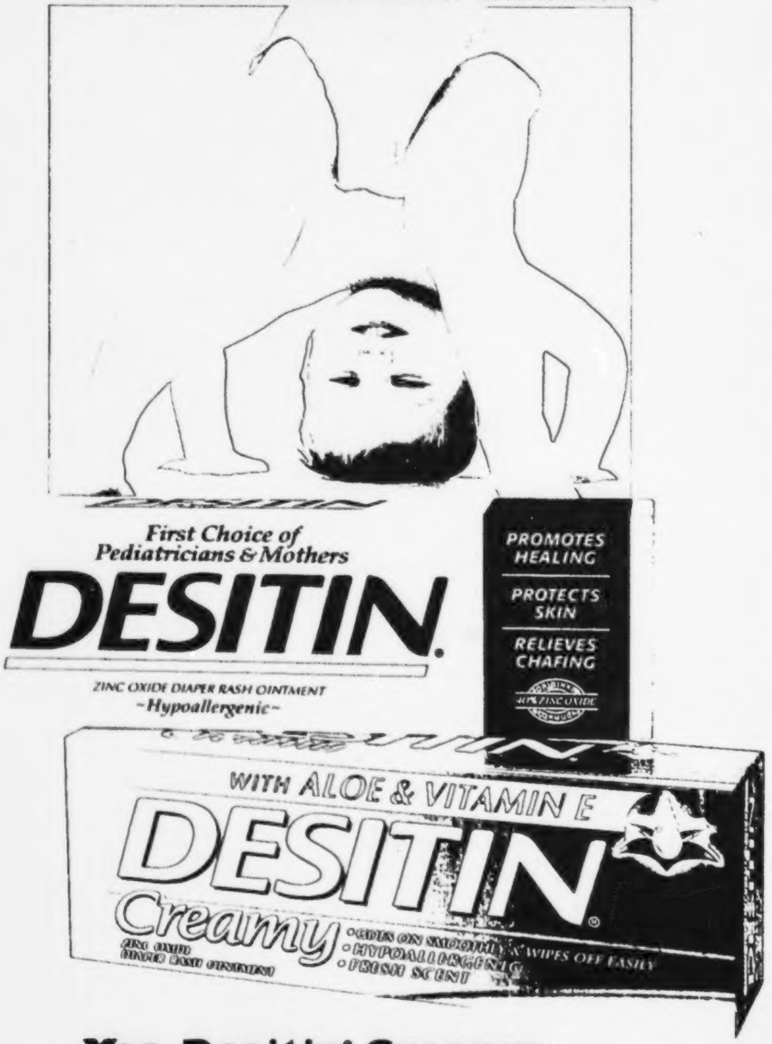
111 Oral Health for People with Disabilities Part XIV: Dental Treatment for Adults
By Paul Farsai, DMD, MPH and Joseph Calabrese, DMD

116 Directory of Schools, Camps & Residences

ON OUR COVER: Special educator Jean Pittmars uses a therapy ball to provide a sensory experience, relaxation and fun for Sierra at The Center for Discovery. Photograph by Will Faller.

EP
Exceptional Parent

Does anything heal and protect precious little bottoms like Desitin®?


First Choice of Pediatricians & Mothers
DESITIN.
ZINC OXIDE DIAPER RASH OINTMENT
~Hypoallergenic~
PROMOTES HEALING
PROTECTS SKIN
RELIEVES CHAFING
WITH ALOE & VITAMIN E
DESITIN®
Creamy
ZINC OXIDE DIAPER RASH OINTMENT
• GOES ON SMOOTHLY & WIPES OFF EASILY
• HYPOALLERGENIC
• FRESH SCENT

Yes, Desitin® Creamy.

Desitin Creamy was shown in a clinical study to work just like original Desitin. Plus, it's so creamy, it glides on smoothly and wipes off gently. Smells nice, too.

Desitin.® More baby doctors choose it. More moms use it.

Circle #72 or visit www.eparent.com/adinfo

contents

DEPARTMENTS

10 Editor's Desk

14 Search and Respond

70 Media Review
BraveKids.org

88 Familiar Faces

90 Organizational Spotlight
By Judit Ungar and Fred Cook
The National Tourette Syndrome Association

94 Tech talk
By Sheryl Burgstahler, Ph.D.
Keeping Kids Safe on the Internet
A look at how to keep internet use safe and enjoyable for your children.

100 Research Reflections
By Dr. Jan Blacher
Twice Exceptional: Learning Disabled and Gifted

104 Legislative Update
Washington Politicos Focus on IDEA Reauthorization

109 What's Happening
• Senate Bill for Disabled Children • Definition of Mental Retardation • BabySpa • National Council on Disability • Straight From Her Heart • National Disability Mentoring Day

110 Further Reading
By Megan Henninger
A look at six different books on various education issues.

118 EP Library

120 New Products

124 Children's Page
By Michelle Boevers
Life Changing Moment

This edition was primarily produced by the efforts of interns Megan Henninger, Julia Steele and Maria Tortoreto under the direction of Laura Apel. We thank them for their efforts as they return to school.

Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy-Ed Corp., dba *Exceptional Parent Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy-Ed Corp. *Exceptional Parent*® is a registered trademark of the Psy-Ed Corp. **Postmaster:** Please send address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *Exceptional Parent*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #4006 0754. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

Exceptional Parent neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
EP advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative nomenclature.

—*Rick Rader, MD*

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

MITCHELL F. BRIN, MD, Vice President, Botox, Allergan, Irvine, CA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics, Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof. Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

HARILYN ROUSSO, ACSW, Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

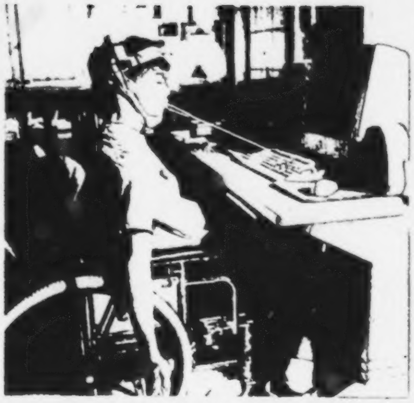
LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

HAROLD TURNER, D.D.S., Editor Emeritus, Oral Health

THERESA VARNET, MSW, JD, Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO



The Center for DISCOVERY

The Center for Discovery is certified by New York State through the State Education Department, the Department of Health and the Office of Mental Retardation and Developmental Disabilities (OMRDD); and by the Commission on Accreditation of Rehabilitation Facilities (carf).

Visit us at Booth #730 at The World Congress & Exposition on Disabilities in Orlando, Florida — October 3-5, 2002

Please read the four-part series, "Transitions: Informing, Empowering and Keeping Parents Involved," (June through September) currently appearing in Exceptional Parent Magazine.

Don't miss the special presentation, "Transitions: Informing, Empowering and Keeping Parents Involved," at the WCD (Oct. 4, at 2:00 p.m.) that will address the issues raised in the four-part EP series.

Be sure to attend the presentation at the WCD (Oct. 3, at 3-5 p.m.) highlighting the outcomes of The Center for Discovery 's International Summit, entitled "Disabilities: Sharing Visions for the Future" that was held at The Center this past June.

The Center for Discovery, a nationally-renowned prep school for children with significant disabilities (including multiple disabilities, medical frailties and some behavioral concerns) recently opened several new, small, universally-designed residences.

Located near Monticello, NY in the picturesque Catskill Mountains, just two hours northwest of New York City, The Center features a nature-based program that challenges children, and their families, to work with us to provide the finest educational, clinical, social and residential opportunities available anywhere.

We may just be the right program for your child.

Call our Admissions Office at (845) 794-1400, extension 1444 for information and/or to arrange a personal tour and see *discovery* in action.

Ask for our new video.

Box 840 / Harris, NY 12742
845-794-1400, extension 1444
email: admiss@sdtc.org

Visit our websites:
www.thecenterfordiscovery.org
www.discoveryifi.org

BEST COPY AVAILABLE

Circle #84 or visit www.eparent.com/adinfo

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Serving Adults having MR/DD

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #20 or visit www.eparent.com/adinfo

EP

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

Editor-in-Chief	Rick Rader, MD
Consulting Managing Editor	Donald P. Mazzella
Medical Editor	Fern R. Potvin
Senior Editor	Laura Apel
Associate Editor	Megan Henninger
Assistant Editor	Julia Steele
Assistant Editor	Maria Tortoreto
Information Systems Coordinator	Dennis Dusevic
Research Assistant	Susan Jenkins
Graphic Consultant	Dennis Wilkes
President, CEO & Publisher	Joseph M. Valenzano, Jr.
VP Business Development & Internet Projects	Vanessa B. Ira
Chief Financial Officer	Dolores A. Kinley
Ad Traffic Manager	Kendra Kelly
Sales Coordinator	Doris DeFina
Receptionist/Public Relations Coordinator	Robyn Sager
Art Direction, Design	Publishers Design Group, Inc. ✉annpdg@aol.com
Production Manager	Michael Longobardi
EP Library	Ron Richards (800) 535-1910 ✉eplibrary@aol.com
Webmaster	Ken Fleischer, Dynamic Media Works ✉webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Vanessa B. Ira
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 ext. 209
✉ vira@eparent.com
CANADA

Annabelle & Gabe Jacobson
(847) 256-6850
✉ bellyon@megsinet.net
MI, WI, IA, IL, IN

Bill Joubert
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ bjoubert@superlink.net
MT, ND, MN, SD, WY, NE, KS, OK, TX

Jared Adams
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉jadams@eparent.com
DE, MD, DC, WV, VA, NC, SC, GA, FL, KY, TN, AL, MS, LA, AR, MO

Matt Valenzano
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 x211
✉mattvalenzano@eparent.co
ME, VT, NH, MA, RI, CT, NY

Brian Regan
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
PHARMACEUTICALS

Larry Battistello
Marketing Plus
3155 East Ramon, Unit #203
Palm Springs, CA 92264
✉ seeme4ads@aol.com
TERRITORY: WA, OR, ID, NV, CA, UT, CO, AZ, NM

Barbara Nastro
65 East Route 4
River Edge, NJ 07661
(908) 534-6366
(908) 534-6941-fax
✉ nastro@blast.net
NJ, PA, SCHOOLS, CAMPS & RESIDENCES, MARKETPLACE

Color Separation/Film Preparation
AGT7 Carlstadt, NJ 07072

List Rentals
GRS
Mktg Services Inc.
187 Billardvale Street
Willington, MA 01887
Attention: Mark Hammar
978-661-8126
mhammar@mktgservices.com

Publishing & Editorial Office
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

Subscriber Service:
Exceptional Parent
P.O. Box 2078, Marion, OH 43306-2178.

Customer Service/New Orders:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

Exceptional Parent magazine was founded in 1971 by Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 106

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #87 or visit www.eparent.com/adinfo

Kelly Bankston ◦ 1981- 2002

You might say I had a "thing" for Kelly Bankston

Although I'm formally trained as a physician, I wasn't Kelly's clinician. My relationship with her was perhaps more natural, more flowing, more mainstream and more comfortable—I was simply her friend.

The sign on the building that houses my office announces to everyone that it's a "habilitation center," and despite the hordes of mail that is addressed to me care of the "rehabilitation" center it's clearly a habilitation center. It's where Kelly liked to hang out when she took her jaunts out of her classroom.

The word "habilitation" comes from the Latin "habilis," meaning to make suitable or to make fit. That is the nature of what we try to do. Rehabilitation, as you might know, is the retraining of skills in people who had them and lost them from degenerative disease, cerebral insults, trauma or accidents. Our folks, including Kelly, never had these skills to begin with—and so the term "habilitation" better defines our goals, our efforts and our hoped-for outcomes. But that certainly is not to imply that Kelly didn't have skills. She had the innate skills to engage people, make friends, challenge people, question their murky beliefs and, with me specifically, to get anything she wanted.

I came to Chattanooga eight years ago and like most physicians had no formal training in developmental disabilities. Most of what I have learned I learned by the seat of my pants—I learned from the parents, my colleagues, and, most dramatically, from Kelly and her classmates. They taught me to abandon my preconceived notions about learning, about abilities, about never ceasing to be amazed.

Mostly they taught me about citizens with special needs, the politically correct term to define people with disabilities. Kelly provided the answer to the age-old question: what's so special about special needs? The answer is "nothing." Kelly's needs, like those of her classmates, like those of you and me, were to be understood, to be considered, to be connected, to be loved, to be authenticated, to be respected and mostly to be needed—the same shared, not special, needs that give my own life meaning and a reason to get up every morning.

She left me with two things – one tangible and the other an image.

She left me a ream of paper with her phone number. At first pigeon scrawls, mostly illegible, more like ancient hieroglyphics or cave wall scratches, and then finally clearly defined, legible letters that began 622—more like the number of hours Kelly and her teacher, Jenny Chase, worked together to transform the pigeon scrawls into ordered, disciplined, controlled and purposeful writing.

By Kelly asking me daily if I had her number, she was announcing to me that we were connected—and she was doing her part to invite me into her inner sanctum of acceptance, friendship and love.

The image she left me is that of her "thumbs up salute" when I would ask her, "How you doing, Kelly?" She reminded me of the images of the young British Royal Air Force pilots giving their thumbs up salute when their Spitfires roared to life and were ready for take-off. Kelly was always ready for take-off, and always ready to take to the skies or the hallways in search of a new adventure, a new encounter or a new experience.

I owe Kelly quite a lot professionally. She and I graced the cover of the August 1995 issue of Exceptional Parent Magazine because of a program we co-developed, designed to teach both new and seasoned doctors the joys and challenges of caring for children and adults with developmental disabilities and shared needs. (By the way, this is the first time the term "special needs" has been replaced by "shared needs", a habit I will try to adhere to from this day on.) The article led to my invitation to join the magazine's Editorial Advisory Board and eventually to become the editor-in-chief. Quite the coup for an upstart in the field.

Kelly—on her first outing as a trained patient simulator at Grand Rounds at Chattanooga's Erlanger Hospital—gave a fumbling intern a lesson which I'm sure will guide her for the rest of her medical career. The intern was invited to come up to the podium and examine Kelly's distinct bony contracture. In front of colleagues, residents, attending physicians, department heads and professors she began to examine Kelly. After several tense moments, Kelly announced to the audience that she thought if the intern removed Kelly's bulky ski parka, the intern might have a better chance of feeling her deformity. I'm sure to this day, if she decided to pursue her profession, that young doctor never examined a patient without removing her jacket. Kelly indeed left her mark on medicine.

Another project that Kelly adopted with élan and enthusiasm was "Kelly's Random Acts of Kindness Cart." (Editor's Desk, EP, January 2002). Kelly and her assistant Anne Patten would patrol the halls at Orange Grove and randomly present gifts to teachers, assistants, therapists, nurses and bewildered visitors simply because she enjoyed the feeling of giving something to someone for no apparent reason.

The cart has been restocked and we're conducting a search to find someone to carry on the tradition that Kelly started and perfected.

Kelly is memorialized here in the pages of Exceptional Parent

BEST COPY AVAILABLE

Magazine and will remain in my heart long after the pages are yellowed, brittle and faded.

"We are spirits. That bodies should be lent us while they afford us pleasure, assist us in acquiring knowledge or in doing good to our fellow creatures, is a kind of benevolent act of God. When they become unfit for these purposes and afford us pain instead of pleasure, instead of an aid become an encumbrance and answer none of these intentions for which they were given, it is equally kind and benevolent that a way is provided by which we get rid of them. Death is that way."

As soon as I find your new area code Kelly I will call you… after all, I do have your number.

Rick Rader, MD, Editor-in-Chief, EP
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Inc.,
Simply Kelly's friend

I've just returned to my office after attending Kelly's service. I smiled and laughed more than I cried. As Kelly's life and personality were reflected by clergy and friends, I, too, took a moment to think about what Kelly meant to me. As I remember, I will think about her visits, usually daily, to my office as she headed to check the classroom mailbox. Kelly, proudly a classroom helper, was sent on a mission and she took that mission very seriously. This was a young lady who could drive her powerchair more efficiently than some drivers on the open road. I was always amazed at her ability to "turn on a dime."

Kelly chatted with me about her family, her friends, her teacher, Jennie, and classroom assistants, Carol and Caroline. Kelly loved people and life—and it was so obvious, while listening to the words spoken at her service: people and life enjoyed Kelly. Heaven, look out! Your new resident is quite a special lady!

Jann Davis, Social Worker, Children's Services

Kelly Bankston was an extraordinary young lady. I have known her since the day she was born. A paragraph isn't enough to express my feelings for Kelly. She would stop by my office almost every day on her way to get the mail. Sometimes she would just wave and keep going; other days she would stop and visit for a little while. I could always count on Kelly to make me laugh. She touched so many people in her 21 years, and I will miss her greatly.

Nina Rains, Technical Support Assistant
Orange Grove Center, Inc.

As a volunteer at Orange Grove Center, I have known Kelly for almost 10 years – about half of her young life. To know Kelly is to love her; I'm no exception to that premise. I sat sadly this week at her funeral service listening to several eulogies appropriately and eloquently expounding on Kelly's virtues and personality. I heard a host of descriptive words and phrases such as cheerful, always smiling, caring, loving, can wrap you around her little finger, etc. I thought how true these accolades were. I marveled at how someone so young could amass such success in influencing the people she met. Then the thought came to me: Kelly is more than a person, she is an illuminating spirit. The twinkle in her eye, the smile on her face, the hugs she gave freely, the thumbs up she gave even when things were not going well and many other indefinable qualities gave those who met Kelly, no matter how fleetingly, a feeling of peace and caring. The world is a little sadder for Kelly not being here, but a lot brighter for her having touched the lives of so many.

No discussion about Kelly would be complete without recognition of her dedicated father, Mark. The two were as one. His untiring devotion and loving care are an inspiration to all fathers and caregivers.

Jim Goldman, Orange Grove Center
Volunteer and Board Member

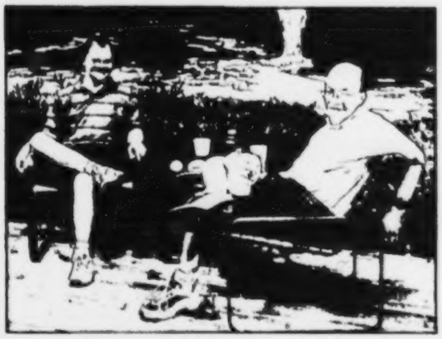
There are so many "Kelly stories," but my favorite is when my mother and I gave Kelly's classroom a surprise Christmas party. My brother played Santa Claus, and every few minutes Kelly could be heard saying "Uncle Charlie." Staying in character, my brother would tell her, "I'm not Uncle Charlie, I am Santa Claus." Kelly let him have his way and at the end of the party she yelled out, "Santa Claus, when you get home, tell Uncle Tommy to call me!"

Rest in peace my darling angel, momma loves you.

Cindy Bankston, Kelly's Mother EP

BEST COPY AVAILABLE

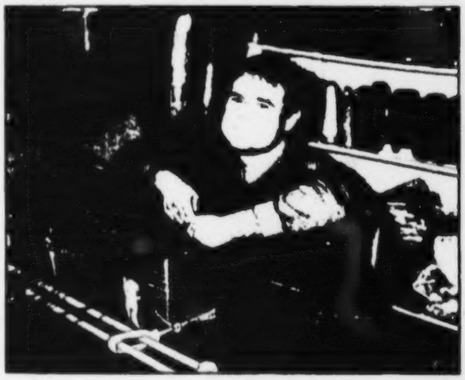
At The Melmark Meadows...



Life begins at 21!

Located on a beautiful 80-acre campus on Philadelphia's exclusive Main Line, Melmark Meadows, a creative community for adults with developmental disabilities, offers countless opportunities for growth...

...a nurturing home away from home



...meaningful work

MAKOS
MELMARK
MAKOS

County
Dr
nty

... and rewarding friendships.

BEST COPY AVAILABLE

All of this and more can be found at The Melmark Meadows, a residential and vocational program for adults with developmental disabilities.

For over 27 years The Melmark Meadows has provided creative careers and participation in music, drama, and the arts.

...a variety of leisure activities

...celebrating life's achievements

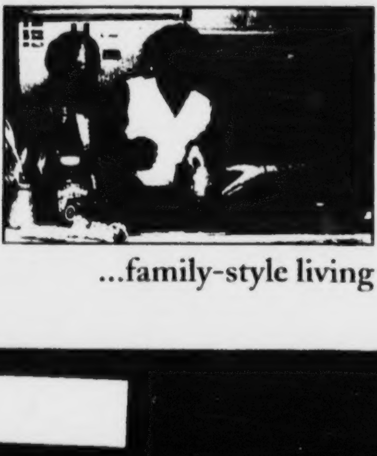
An Internationally Recognized Model of Living and Learning

- Consultation, seminars, workshops
- International professional training center for therapists, instructors, interns
- Community Master Gardener program site
- Member of the American Horticulture Therapy Association
- Staff affiliations with the University of Pennsylvania and other local universities.

THE MELMARK MEADOWS ®

A Creative Community for Adults with Developmental Disabilities

2600 Wayland Road, Berwyn, PA 19312
For more information call:
Peter McGuinness, Director of Admissions
1.888.Melmark • www.melmark.org



...family-style living

EST COPY AVAILABLE

Circle #64 or visit www.eparent.com/adinfo

Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S Looking for Advice with attached Chromosomes

My daughter was diagnosed with Chromosome 5 attached to Chromosome 15. The doctors still have not determined what effect this will have on her. She was born with a cleft palate, long and slender fingers, small ears with a fold on top and small facial features. We have been told that she does not have club feet but that they are shaped as if the tops of her bones are overlapping. She has slight hearing loss due to her ear canals being too small. She does not seem to have any cognitive delays, although the doctor says that it is hard to tell with her being so small. Can anyone whose children have similar symptoms offer advice?

—KS, via EP Web Site

S Short Gut Syndrome

I am looking for information on Short Gut Syndrome. I am the prospective adoptive parent of a three-year-old who has never eaten by mouth and I am hoping that she will. I would greatly appreciate parents sharing their experiences of helping their children convert from enteral tube feeding to oral feeding.

—CH via EP Web Site

S Seizure questions

My one-year-old son has lissencephaly and seizures called infantile spasms. Now that he is getting older, the doctors are calling the seizures by some other name. Does anyone else have experience with this?

—A, via EP Web Site

S Looking for diagnosis

We have a beautiful 16-month-old daughter who was born at 36 weeks measuring 18 inches and 6.9 pounds. At present she is 27 inches and 16 pounds. She has been diagnosed with "failure to thrive" because she does not eat enough on her own (even though her suck is strong enough) and has delayed gross motor skills. In prone position she has extreme difficulty pushing up on her arms and therefore cannot roll from stomach to back. She is able to sit on her own but cannot get into the sitting position, crawl or walk on her own. She has very loose joints and low muscle tone. Since three months she has been fed through an NG tube and now has a G-tube. She does not eat solid foods but will put them in her mouth and then not swallow. The doctors have ruled out cystic fibrosis, and Prader-Willi and Williams syndromes. All blood work and CT and MRI scans are fine. We are now awaiting an experimental chromosome test. If anyone has any idea what my daughter may have, we would greatly appreciate any help.

—D&CP via EP Web Site

S Communication problems

I am trying to find some alternative ways of being able to communicate with my son. He is a five-year-old developmentally delayed child who has vision and hearing impairments and is non-verbal. The school and I have been trying to teach him ASL, and he has learned just over 50 signs. The problem is that he is getting increasingly frustrated and starting to have behavior problems. I think that we need to find other means for him to communicate his wants and needs. Does anyone know a place where I can look for help?

—PA, via EP Web Site

S Lattice Corneal Dystrophy

My grandson has been diagnosed with Lattice Corneal Dystrophy. He cannot handle being in strong light or sun light. Does anyone else have or know a child that has this disorder?

—DE via EP Web

S Ring chromosome 14

I have a 16-year-old son who was born with ring chromosome 14, a very rare condition. Does anyone else have a child who is suffering from the same disorder who can offer advice?

—LM, via EP Web Site

continued on page 19

Convaid

- 10 - 45° adjustable tilt
- 90 - 105° of seat back angle adjustment
- Rodeo 12" weighs only 23 pounds with footplate
- Adjustable seat depth grows with the child
- Height adjustable push handle for parent's comfort
- Optional storage tray under frame
- Folds at any angle of tilt
- Folds with all positioning options in place
- Available in 7 bright colors

Rodeo

New Lightweight

Tilt Chair

Compact Folding

Looking for a compact, yet lightweight tilt chair? The Rodeo tilt-in-space chair is just that, it has 10 – 45° adjustable tilt and a seat-to-back angle adjustment from 90 - 105°. Key features include an adjustable height handle, angular adjustable footplate, elevating legrests and an optional tray located under the chair for storing medical necessities/auxiliary equipment. The seat depth is adjustable allowing for years of use, and a wide variety of comprehensive positioning options are also available.

Call **1-888-CONVAID** today for your free brochure and product video. Or visit us online at **www.convaid.com** for more information.

Convaid MADE IN THE U.S.A.

091

Circle #34 or visit

www.convaid.com

PO Box 4209, Palos Verdes, CA 90274 USA • Tel 1-888-CONVAID (266-8243) / FAX 310-618-8811

HARD MANUFACTURING

AGE APPROPRIATE BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas

The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #48 or visit www.eparent.com/adinfo

EP
has the information an "Exceptional Parent" like you needs

EP
Exceptional Parent

Your paid subscription includes the EXCEPTIONAL PARENT 2003 Annual Resource Guide, which normally sells nationally for $19.95.

This invaluable reference tool is a "must-have" for exceptional parents

Save $5.00
by ordering on-line at:
www.eparent.com
For telephone orders call:
877-372-7368

Circle #199

Subscribe and be part of a network of "Exceptional Parents"

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 Issues) $39.95 ☐ 2 Years (24 Issues) $65.95 ☐ 3 Years (36 Issues) $97.95
US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.
Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______ Exp. Date ______
Name ______
Address ______
City ______ State ______ Zip ______
E-mail ______ Yes, I want more information to help me everyday.
Signature ______ E-mail ______

BSEP2

Subscribe and be part of a network of "Exceptional Parents"

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 Issues) $39.95 ☐ 2 Years (24 Issues) $65.95 ☐ 3 Years (36 Issues) $97.95
US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.
Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______ Exp. Date ______
Name ______
Address ______
City ______ State ______ Zip ______
E-mail ______ Yes, I want more information to help me everyday.
Signature ______ E-mail ______

BSEP2

Make someone a part of a network of "Exceptional Parents"

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 Issues) $39.95
☐ 2 Years (24 Issues) $65.95
☐ 3 Years (36 Issues) $97.95
US funds vary. Canada $54.95 per year.
Other foreign countries $57.95 per year.

993

PLEASE SEND MY GIFT OF EP TO:
Name ______
Address ______
City ______
State ______ Zip ______

THIS GIFT IS FROM:
Name ______
Address ______
City ______
State ______ Zip ______

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______
Exp. Date ______
Signature ______

Save more money: Order off the Web: www.eparent.com

XSEP2

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

994

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer lif for themselves and for their children.

Exceptional Parent's MISSION
IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

continued from page 14

S

Medically fragile in the classroom

My son has pulmonary hypertension and his cardiologist has recommended that he receive homebound services for kindergarten and stay away from other children, especially during the winter months. Andrew really wants to attend school with the other children. Any suggestions about how to accommodate a medically fragile child in the classroom?

—A, via EP Web Site

S

Seeking information on cochlear implants

My three-year-old son is being considered for a cochlear implant. He also has cerebral palsy and vision problems. I would like to know more about the implants and how a child is tested for them.

—DD, via EP Web Site

Respond

R

Sign language concerns

182 has a five-year-old grandson with Down syndrome and wants to know if she should concentrate on sign-language to communicate.

I have an eight-year-old daughter with Down syndrome. When she was younger, we opted to forgo sign language, as we were concerned she would become dependent on it. Of course there is no way of knowing if we made the right choice or not. Just this year, her therapists have incorporated some signing and her speech continues to improve. Most people (even those not familiar with her) understand some of what she is saying now. If your grandson hasn't gotten this, I am sure it is never too late to start. I just thought another experience might give you some encouragement. Best of luck.

—D, via EP Web Site

R

Dental care

210 (June, 02) has a 20-year-old son who is mentally retarded with a dental cavity and is seeking advice on how to handle dental care with special needs children.

I am an anesthesiologist and the parent of a 17-year-old with severe developmental delays. My son requires general anesthesia for dental work and other examinations. First of all, you need to find a dentist who is experienced in working with patients under anesthesia. You can call your local children's hospital, ask for the anesthesiologist on call and ask which dentists frequently bring patients into the operating room for dental work. There are many things you can do to help the procedure go more easily. Ask your physician for EMLA cream. This is a local anesthetic cream that can be applied to numb the skin so that he will not feel the IV needle. It needs to be applied two hours before starting the IV. You can ask to stay with him until he is asleep and be called to be with him before he wakes up, if this would help him remain calm. You will need to find out whether he will need to be completely asleep or just sedated (there are pros and cons to both), depending on what needs to be done and what you anticipate his reaction will be. If he does need to be completely asleep, ask for something to prevent vomiting. Anesthesia is extremely safe these days, but because of the special needs issues you have to be a little more demanding than the average parent usually is.

—AH, via EP Web Site

There are several options to control the movements of your son so that his dental care can be completed. One such option is to admit your son to a surgical center for outpatient general anesthesia. In many large cities there are anesthesiologists who have office-based practices and will come to the dentist's office to administer the anesthesia. If your son will not allow his dentist even to clean his teeth, then starting an IV line will be a challenge. An anesthesiologist can sedate your son in such a way so that an IV line can be started safely and without injuring your son. Office based anesthesia administered by someone other than the doctor performing the dental procedure is both cost effective and far safer than any other method.

—RS, DDS, via EP Web Site

My 13-year-old son, who has cerebral palsy, has a wonderful dentist whom he sees regularly. Fourteen months ago, he had an accident that necessitated emergency oral surgery. The oral surgeon expertly put him to sleep to do the work. A few months ago, as a result of this same accident, my son needed a root canal. The endodontist performed the work at the oral surgeon's office so that my son could again be put to sleep. This coordination was essential in completing the work.

—TB, via EP Web Site

R

Botox injections

54 has a nine-year-old daughter with cerebral palsy and is looking for information on botox injections.

Our nine-year-old daughter has CP and went three times for Botox. There is a great report on Botox in the May 2002 issue of EP explaining everything we parents must know before doing it. There are no side effects and it helps a lot with movement disorders. I hope it helps you.

—PC, via EP Web Site

Our 4-year-old son just had botox injections in his legs. I was really worried about the pain issue as well, but am happy to report that-with a dose of ibuprofen before, and comforting right

continued on page 20

continued from page 19

afterwards-he did very well. Hope it goes as well for you.

—*H, via EP Web Site*

School Harassment

598 (August, 02) has a 14-year-old son who has mild to moderate mental retardation, a speech difficulty and learning disabilities. He is being harrassed at school by non-special-ed classmates.

IDEA requires your district to provide a program for your child in the "least restrictive environment." That means that if your child can handle an integrated setting, he must be provided with one. That might not solve the harassment problem, but the more other children interact with him, the more they will understand him. You may also want to press for staff training in diversity and have the school add tolerance to their curriculum. While most professionals hate to see anyone ridiculed, they sometimes lack the tools to adequately prevent it.

—*L, via EP Web Site*

An accessible bathroom

193 needs help in designing a bathroom for a seven-year-old son with severe disabilities.

I recently had my son's bathroom remodeled through Assistive Technology. The cost was all donated by the program. They installed a preschool-size potty that was very low to the floor, but otherwise completely normal in appearance. This is great for my son, who has short stature due to Robinow Syndrome. I would call large plumbing supply stores and ask if they carry these toilets. You want one with a tank and not the open plumbing in the back like you may see at a school. We also had his bathroom vanity remodeled to his height. The sink handle is on the side (not the back) and the water flow is controlled by lever handles instead of knobs. We also had a sensor installed on his light so that when he enters the bathroom it automatically comes on and stays on until it no longer senses motion. These are only about $30 or less plus the cost of installation. Maybe you can ask a local plumber or electrician in your area to donate the installation of any of these items. You might be amazed that they will do it for free to help out a child. Good Luck.

—*KO, via EP Web Site*

Behavior concerns

653 has a eight-year-old son with Down syndrome and is looking for help with behavior problems in school.

I'm not sure what state you are in, but I would check to see if there is a behavioral specialist in the school system. I live in Loudoun County, Virginia, and have an eight-year-old daughter with Down syndrome. If a behavior becomes an issue, they bring in a specialist who observes the child to see if they can find out what is causing the behavior. The specialist then works with the teacher and the parents, if it is necessary, to come up with a proper plan to stop the behavior. Feel free to contact me if I can be of any further help. Best of luck to you.

—*DD, via EP Web Site*

Wheelchair capabilities

597 (July, 02) has a son with spina bifida and is looking for a way that he can use a wheelchair in their grass yard.

We have had a beach wheelchair from Surf Chair of Daytona Beach, Florida, for about four years. It is just great! It will go over sand, snow or other uneven terrain. This chair is both sturdier and less expensive than many others on the market. It is also one of the few that is made with marine-quality components, so that it can withstand oceans and salt water. When we bought ours, Surf Chair was selling a high and a low (standard) model. Although we are happy with our higher chair, we find we could have gotten along with the lower model, and it would have put more weight nearer the ground—perhaps a little safer. The chair we have is easy to push, however, and our son is a big guy. It may be that Surf Chair makes a folding model by now. I got their number from the Daytona Beach Chamber of Commerce, who told me a town lifeguard began making sand chairs after he witnessed too many beachgoers struggling to get to the water. Another way you might approach this is to see if someone on this web site has a beach chair they are not using. Also, some beaches have beach chairs available free, but you may want to call ahead or arrive early to get one.

—*PJ, via EP Web Site*

Controlling seizures

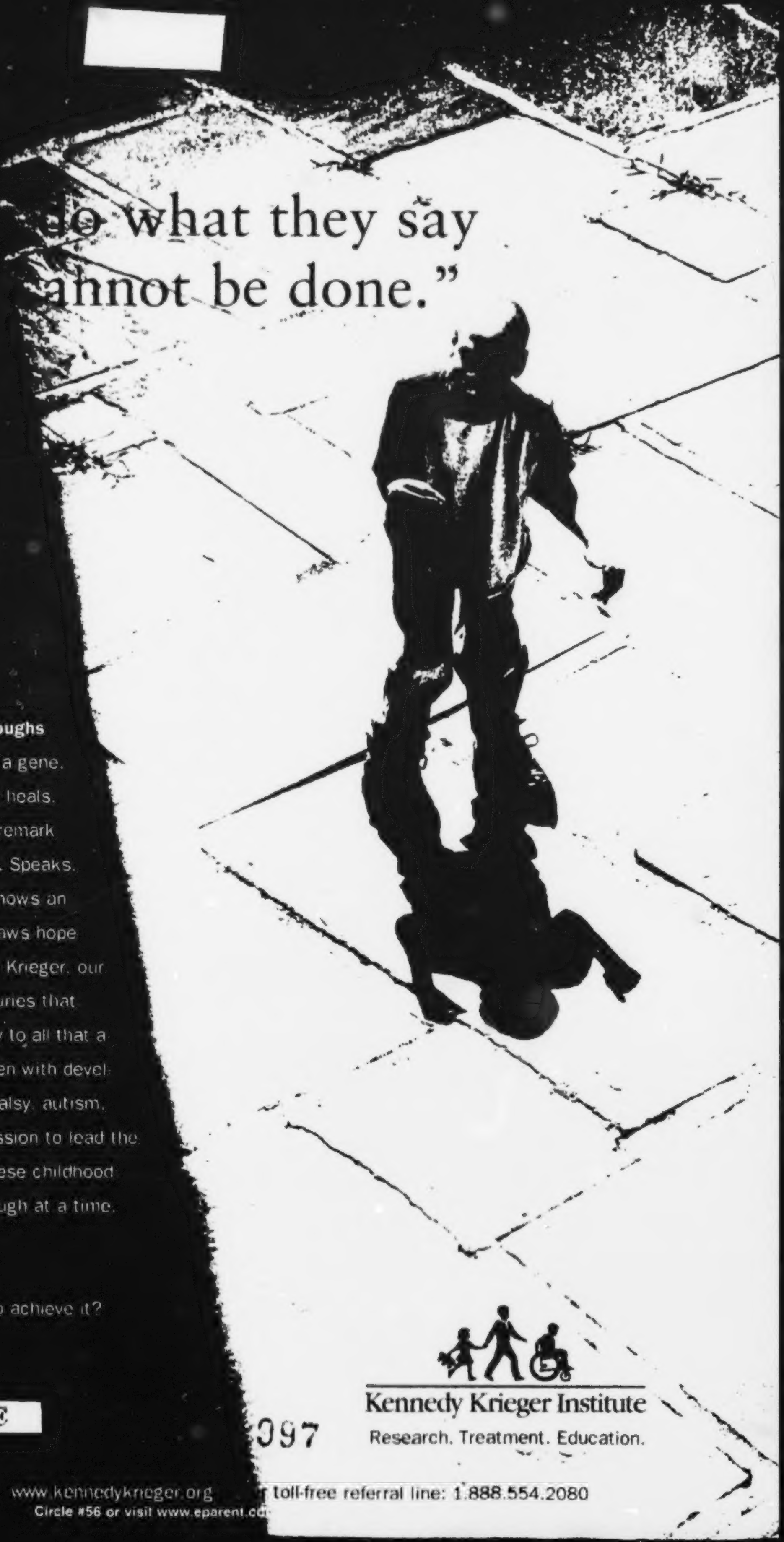
A&RM have a four-year-old daughter who is experiencing seizures. They have tried many medicines that have not succeeded in helping her.

My son is on Topomax for his seizures as well as Klonopin. With these two medications, his seizures have been under control. However, what you are describing also sound like symptoms of gastroesophageal reflux with the arching, crying and agitation. My son has reflux and is on Prilosec which has helped tremendously. You may want to consult with your pediatrician or gastroenterologist regarding this possibility.

—*SE, via EP Web Site*

Regarding seizure control, after trying over 30 medications, our 16-year-old daughter had a vagal nerve stimulator implanted. It was slow to work but we managed to get to mono-therapy for over six months. It works better for some kids and not at all for others. She is now having more seizures but VNS did allow her a better quality of life. I hope that you have the same success.

—*JT, via EP Web Site*



At Kennedy Krieger, dramatic breakthroughs are made everyday. A scientist isolates a gene. A therapist unravels a mystery. A doctor heals. A teacher connects. And then, the truly remarkable breakthroughs begin. A child walks. Speaks. Ties his shoe. Remembers her name. Knows an answer. Makes a friend. And a family draws hope where once there was none. At Kennedy Krieger, our sole focus is on those problems and injuries that affect a child's developing brain - the key to all that a child is and can become. We treat children with developmental disabilities such as cerebral palsy, autism, Down syndrome and others. It is our mission to lead the way in the research and treatment of these childhood brain disorders. One dramatic breakthrough at a time.

Every child is born with great potential. Shouldn't every child have the chance to achieve it?

Kennedy Krieger Institute
Research. Treatment. Education.

www.kennedykrieger.org r toll-free referral line: 1.888.554.2080
Circle #56 or visit www.eparent.c

EST COPY AVAILABLE

BRADY
EPILEPSY
DAILY SEIZURES
MULTIPLE MEDICATIONS
FLUNKING SCHOOL
EXHAUSTION
ER VISITS EVERY MONTH
FALLING
LIVING IN A HELMET
A SEIZURE EVERY FEW MONT
ONE MEDICATION
ALL B'S
ENERGY
ONE ER VISIT LAST YEAR
FOOTBALL
HANGING OUT WITH THE GUY

BEST COPY AVAILABLE

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

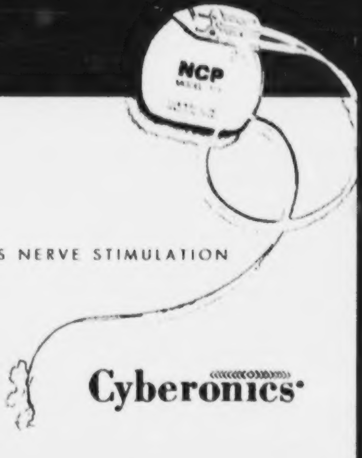
So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, your doctor about adding VNS Therapy. It's not brain surg It's a medical device the doctor implants in the chest, leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, no debilitating side effects, and improvement in alertne fatigue and mood. Some patients are even helped dramatically as Brady, although VNS results may vary.

BEST COPY AVAILABLE



VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS THERAPY

VAGUS NERVE STIMULATION

Cyberonics

Circle #38 or visit www.eparent.com/adinfo

EXECUTIVE SUMMARY[1]
SAFETY INFORMATION
FOR THE NCP® SYSTEM

INTENDED USE / INDICATIONS – UNITED STATES

The NCP System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures which are refractory to antiepileptic medications.

CONTRAINDICATIONS

- The NCP System cannot be used in patients after a bilateral or left cervical vagotomy.
- Do not use short-wave diathermy, microwave diathermy, or therapeutic ultrasound diathermy on patients implanted with the NCP System. Diagnostic ultrasound is not included in this contraindication.

WARNINGS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals. This is not intended to serve as a substitute for the complete NCP System Physician's Manual.

⚠ The **safety and efficacy** of the NCP System has not been established for uses not covered in the "Intended Use/ Indications" section of the manual.

⚠ The safety and efficacy of the NCP System treatment has not been established for stimulation of the **right vagus nerve** or of any other nerve, muscle, or tissue.

⚠ **Excessive stimulation** at a combination of high frequency (≥ 50 Hz) and an excess duty cycle (that is, one that occurs when ON time is greater than OFF time) has resulted in degenerative nerve damage in laboratory animals. An excess duty cycle can be produced by continuous or frequent magnet activation (> 8 hours), as determined by animal studies. Cyberonics recommends against stimulation at these combinations of ranges.

⚠ **Aspiration** may result from the increased swallowing difficulties reported by some patients during stimulation. Patients who have **pre-existing swallowing difficulties** are at greater risk for aspiration.

⚠ **Device malfunction** could cause painful stimulation or direct current stimulation. Either event could cause nerve damage and other associated problems. Patients should be instructed to use the magnet to stop stimulation if they suspect a malfunction, and then to contact their physician immediately for further evaluation. Prompt surgical intervention may be required if a malfunction occurs.

⚠ Susceptible patients with predisposed cardiac conduction systems (re-entry pathway) have not been studied as part of controlled clinical trials to establish the safety of NCP system treatment in these patients. Evaluation by a cardiologist is recommended if the family history, patient history, or electrocardiogram suggests an abnormal cardiac conduction pathway. Serum electrolytes, magnesium, and calcium should be documented before implantation. Post-implant electrocardiograms and Holter monitoring are recommended if clinically indicated.

⚠ **Sudden unexplained death in epilepsy (SUDEP):** Through August 1996, 10 sudden and unexplained deaths (definite, probable, and possible) were recorded among the 1,000 patients implanted and treated with the NCP device. During this period, these patients had accumulated 2,017 patient-years of exposure. Some of these deaths could represent seizure-related deaths in which the seizure was not observed, at night, for example. This number represents an incidence of 5.0 definite, probable, and possible SUDEP deaths per 1,000 patient-years. Although this rate exceeds that expected in a healthy (nonepileptic) population matched for age and sex, it is within the range of estimates for epilepsy patients not receiving vagus nerve stimulation, ranging from 1.3 SUDEP deaths for the general population of patients with epilepsy, to 3.5 (for definite and probable) for a recently studied antiepileptic drug (AED) clinical trial population similar to the NCP System clinical cohort, to 9.3 for patients with partial onset epilepsy.

⚠ **The NCP device is not curative:** Physicians should warn patients that the NCP System is not a cure for epilepsy and that since seizures may occur unexpectedly, patients should consult with a physician before engaging in un-supervised activities, such as driving, swimming, and bathing, and in strenuous sports that could harm them or others.

⚠ **Obstructive Sleep Apnea:** Patients with obstructive sleep apnea (OSA) may have increased apneic events during stimulation. Cyberonics recommends care when treating patients with preexisting OSA. Lowering stimulus frequency or prolonging OFF time may prevent exacerbation of OSA.

PRECAUTIONS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals.

⚠ **Laryngeal irritation** may result from stimulation. **Patients who smoke** may have an increased risk of laryngeal irritation.

⚠ **Dyspnea** may result from stimulation. **Patients with chronic obstructive pulmonary disease** may have an increased risk of dyspnea.

⚠ It is important to follow **recommended implantation procedures and intraoperative product testing** described in this manual. During the intraoperative Lead Test, rare incidents of bradycardia and/or asystole have occurred. As of October 1998, approximately 3,000 patients had been implanted with the NCP System. Four of these patients were reported to have experienced **bradycardia and/or asystole** during the intraoperative Lead Test. All four patients recovered without sequelae. One of the four patients was implanted with the NCP System. There were no postoperative or VNS-treatment-related cardiac adverse events later reported for that patient. No similar events were reported to have occurred during the clinical studies at the time of implantation or during treatment. The safety of this therapy has not been systematically established for patients experiencing bradycardia or asystole during NCP System implantation.

⚠ **Reversal of lead polarity has been associated with an increased chance of bradycardia** in animal studies. It is important to make sure that the Lead connector pins are correctly inserted (white marker to + connection) into the Pulse Generator header.

⚠ It is important to follow **infection control procedures**. Infections related to any implanted device are difficult to treat and may require that the device be explanted. Cyberonics recommends that the patient be given antibiotics preoperatively. The surgeon should ensur that all instruments, including the NCP Tunneling Tool, are sterile prior to the operation.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve** in the neck area inside the carotid sheath.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve below where the superior and inferior cervical cardiac branches separate from the vagus nerve.**

⚠ **A neck brace** can be used by the patient for the first week to help ensure proper Bipolar Lead stabilization.

Environmental and Medical Therapy Hazards

⚠ Patients should exercise reasonable caution in avoiding devices that generate a **strong electric or magnetic field.** (For examples, see the "Other Environmental Hazards" section of the Physician's Manual.) If a Pulse Generator ceases operation while in the presence of electromagnetic interference (EMI), moving away from the source may allow it to return to its normal mode of operation.

⚠ NCP System operation **should always be checked** by performing device diagnostics after any of the procedures mentioned in the Physician's Manual.

⚠ Because of where the Pulse Generator is implanted in the chest, **patients may need to be specially positioned in mammography equipment for clear imaging**. Otherwise, the device may be seen as a shadow on the mammogram. (Most routine diagnostic procedures, such as fluoroscopy and x-radiography, are not expected to affect system operation.)

⚠ **Therapeutic radiation** may damage the Pulse Generator's circuitry, although no testing ha been done to date and no definite information on radiation effects is available. Sources of such radiation include therapeutic x-rays, cobalt machines, and linear accelerators. The radiation effect is cumulative, with the total dosage determining the extent of damage. The effects of exposure to such radiation can range from a temporary disturbance to permanent damage, and may not be detectable immediately.

⚠ **External defibrillation** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for external defibrillation.

⚠ **Electrocautery surgery** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for electrocautery surgery.

⚠ **Magnetic resonance imaging** (MRI) should not be performed with a magnetic resonance body coil in the transmit mode. The heat induced in the Bipolar Lead by an MRI body scan can cause injury.

Use caution when other MRI systems are used, since adverse events may occur because o different magnetic field distributions.

⚠ No scan in which the radiofrequency (RF) is transmitted by the body coil should be done on a patient who has the NCP System. Thus, protocols must not be used which utilize local coils that are RF-receive only, with RF-transmit performed by the body coil. Note that some RF head coils are receive only, and that most other local coils, such as knee and spinal coils, are also RF-receive only. **These coils must not be used in patients with the NCP System.**

⚠ **Therapeutic ultrasound.** Routine therapeutic ultrasound could damage the Pulse Generator and may be inadvertently concentrated by the device, causing harm to the patient.

⚠ **Extracorporeal shockwave lithotripsy** may damage the Pulse Generator. If therapeutic ultrasound therapy is required, avoid positioning the Pulse Generator part of the body in the water bath or in any other position that would expose it to ultrasound therapy. If that positioning cannot be avoided, program the Pulse Generator output to 0 mA for the treatment, and then after therapy, reprogram the Pulse Generator to the original parameters.

Diagnostic ultrasound is not expected to affect the NCP System.

⚠ The Pulse Generator may affect the operation of **other implanted devices,** such as cardia pacemakers and implantable defibrillators. Possible effects include sensing problems and inappropriate Pulse Generator responses. If the Pulse Generator patient requires concurrent implantable pacemaker and/or defibrillator therapy, careful programming of eac system is necessary to optimize the patient's benefit from each device.

ADVERSE EVENTS

Adverse events reported during clinical studies as statistically significant are listed in alphabetical order Ataxia (muscle movements or twitching, generally associated with stimulation); Dyspepsia (indigestion); Dyspnea (difficulty breathing, shortness of breath); Hypesthesia (impaired sense of touch); Increased coughing; Infection; Insomnia (inability to sleep); Laryngismus (throat, larnx spasms); Nausea; Pain; Paresthesia (prickling of the skin); Pharyngitis (inflammation of the pharny throat); Voice alteration (hoarseness);Vomiting.

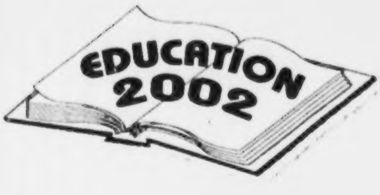
Other potential adverse events possibly associated with surgery or stimulation include but are n limited to the following:

Aspiration (fluid in the lungs); Blood clotting; Choking sensation; Damage to nerves or vasculature i the surgical area, including the carotid artery and jugular vein; Device (Generator and/or Lead) migration or extrusion; Dizziness; Dysphagia (difficulty swallowing); Duodenal ulcer, gastric ulcer; Ear pain; Facial flushing; Facial paralysis, paresis; Foreign body reaction to implants, including possible tumor formation; Formation of fibrous tissue, pockets of fluid; Heart rate and rhythm changes; Hiccuping; Incision site pain; Irritability; Laryngeal irritation (sore, painful throat); Left hemidiaphragm paralysis; Left recurrent laryngeal nerve injury; Left vocal cord paralysis; Low-grade fever; Muscle pain; Neck pain; Nerve injury; Painful or irregular stimulation; Skin, tissue reaction; Stomach discomfort; Tinnitus (ringing in the ears); Tooth pain; Unusual scarring at the incision site; Urinary retention; Vagus nerve paralysis; Weight change; Worsening of asthma and bronchitis; Worsening of cardiac abnormalities, including heart rate and rhythm.

⚠ Patients who manipulate the Pulse Generator and Bipolar Lead through the skin may damag or disconnect the Bipolar Lead from the Pulse Generator and/or possibly cause damage to t vagus nerve.

---

[1] The information contained in this Executive Summary for Physicians represents partial excerpts of important prescribing information taken from the *NCP Pulse Generator Physician's Manual*. The information is not intended to serve as a substitute for a complete and through understanding of the material presented in all of the Physician Manuals for the NCP System and its component parts nor does this information represent full disclosure of all pertinent information concerning the use of this product, potential safety complications, or efficacy outcomes.



EP's TEACHERS of the Year

By Maria Tortoreto

This nation is blessed with extraordinary teachers. Among these selfless molders of our youth are teachers who choose to help educate children with disabilities. For our education issue this year, we have asked our readers to tell us about some of these "Gold Star" professionals who go that extra mile for special children.

The nominees are listed by state, in alphabetic order and with comments from those who nominated them.
Not every state is listed as only those teachers nominated by a parent or peer were considered and will receive a certificate of distinction. If you have a favorite teacher, please send his or her name and your comments to us. We need your help to expand this recognition program for next year!

All of us had a favorite teacher growing up. The teacher who was everyone's friend, who made even the worst subjects interesting, the one who encouraged scribbling poetry on the back of notebooks, the one who still remembers when he/she had our older sibling in class. They may not have profoundly changed our lives by helping us pass a chemistry midterm, but at the time we appreciated it, and we will always remember them by their willingness to help. Those are the good teachers.

But when a child has special needs and cannot physically, mentally or emotionally handle the pressures of conventional learning, a new approach must be taken. These children can be placed in regular education classrooms or in smaller special education programs, but some prosper only when given one-on-one attention in a custom fit routine. Either way, special needs students need confidence, a desire for knowledge, and, most importantly, a special person who can offer that to them. These special people must wholeheartedly believe in the child's abilities, and without them, great success is rarely achieved. Special people such as these do profoundly change lives. These are the exceptional teachers.

These teachers go above and beyond the call of duty for their students.

These teachers go above and beyond the call of duty for their students. They are dedicated to their work, often working extra hours inside and outside of the classroom to help their students succeed. Undying patience, creativity, and charisma day after day are the necessary factors in the success of students, and for many special needs educators these characteristics come naturally. In most cases these teachers are underpaid for their invaluable work, but they do it willingly and lovingly. After all, a simple "thank you" years later can make their jobs worth every minute. These outstanding individuals may not often be recognized for their work, but their work is certainly appreciated.

However big an impact a teacher or mentor can make on a child's life, it is important for him or her to realize that other people influence the child as well. Many of these teachers constantly ask for feedback and suggestions from parents and other teachers, and work those into the child's program. Often they work with administrators in the school district to acquire necessary support or funding. They take the time to continue their own education on disabilities, and they lead workshops for others in the community.

Craig Phillips of Kansas, a vision specialist working with Jessica Lawler, who has a visual field cut, created special glasses for her teachers so that they could understand how she sees the world. Joanne Boyer, a third grade teacher in Pennsylvania who had Scott Exler, a boy suffering from

continued on page 29

1001

TEACHERS OF THE YEAR

CALIFORNIA

Judy Coryell
Penfield School, Ventura
"Judy is the greatest, most loving, spectacular person. I am so glad she has been my little one's teacher."

Lisa Venske
Gidley School, El Monte
"She truly loves what she does and without a doubt, she loves the children."

FLORIDA

Marcy Hersch
Nova Southeastern University, Davie
"She has charisma and a dynamic with the moms and our kids!"

Debby Jones
First United Methodist School, Kissimmee
"This is a teacher who doesn't know the meaning of 'can't.' She has been a beacon of courage to our children."

Luanne Key
Mill Creek Elementary School, Kissimmee
"Mrs. Key has helped our family tremendously. This lady has a heart of gold."

Marisol Rodriguez
Thacker Avenue Elementary, Kissimmee
"The exceptional student populations are so fortunate to have such a good teacher."

Gillian Biggers
Mill Creek Elementary School, Kissimmee
"She has helped so many autistic children move on… she is very good at what she does."

Ruth Howell *
Ocean Breeze Elementary School, Indian Harbour Beach
"After coming out of a self-contained class into a regular class, Ruth made my son's sixth grade year a successful one."

Valerie Lundin
Cotee River Elementary, New Port Richey
"Val is the best thing that has happened to our school and our county's Special Olympics program."

GEORGIA

KK Springer
Joseph Sams School, Fayetteville
"She is very motivational with the children. She takes the time to make things work."

Hilda Taylor
Arcado Elementary School, Lilburn
"Hilda Taylor has a gift for making students beam with pride at their own successes."

IDAHO

Carrie McKay
Whitman Elementary School, Lewiston
"My son not only got an education, but also love and attention from a truly dedicated person."

IOWA

Emily Thatcher
Roland-Story High School, Story City
"Emily strives to make it possible for her students to have every opportunity to grow and learn."

KANSAS

Craig Phillips
Lawrence Public Schools, Lawrence
"Mr. Phillips has taught my child how to get around in the world."

LOUISIANA

Karla Ritter
Myrtle Place Elementary School, Lafayette
"She takes the extra time with the child, keeps open communications with parents and is not afraid to voice her opinion."

MASSACHUSETTS

Kerry Ann
Next Generation Children Centers, Westborough
"Kerry and her co-teacher Mary Beth are what every parent considers a gift!"

Zarrin Atkins
Apple Valley Montessori School, Sudbury
"Zarrin proved that through a fully inclusive program my daughter could function successfully in an educational environment."

Joan Bregy
Community Therapeutic Day School, Lexington
"She has turned my daughter's whole school experience around!"

Janis Chapman
Memorial Park School, Rockland
"She is a super person that a parent can talk to on any level. She has made a world of difference with my child."

Susan Ciaccio
Westford
"Sue is a very big asset to this community, and is very much respected by her coworkers and the school administration."

*** Teachers with an asterisk are not special education teachers, but were nominated for their work with children with disabilities.**

1002

BEST COPY AVAILABLE

Susan Dauphin •
Taft School, Uxbridge
"She has made a huge impact on the path we found for our daughter."

Julia Hendrix •
Carlisle Public Schools, Carlisle
"Julia meets all students' individual needs instinctively. She is a true professional dedicated to teaching."

Janet Libby
North Reading
"My daughter has exceeded expectations because of the devotion and caring of Janet Libby."

Magnolia Monroe-Gordon
Quincy E. Dickerman School, Dorchester
"She has an amazing capacity to teach students regardless of their needs."

Lydia Shields
Miller Intermediate Elementary School, Holliston
"Mrs. Shields has chosen to accept each of Stephanie's challenges as an opportunity for growth."

MINNESOTA

Brad Wing
District # 287, Plymouth
"I consider Brad to be a friend, and one of those professionals who will always stand out."

Deb Zenker
Gillette Children's Specialty Healthcare, St. Paul
"Deb is warm and caring and makes each kid feel special."

MISSOURI

Kelli Harig
Hazelwood Early Childhood, Florissant
"She is kind and patient. Mrs. Harig made such an impression on me the first time I met her that I asked for my son to be placed in her class."

NEW JERSEY

Donald Brubaker •
Clara Barton Elementary School, Cherry Hill
"His never-ending kindness and knack for facilitating Kelly's inclusion touched me and opened doors for Kelly."

Joanne Keston •
Center Grove Elementary, Randolph
"She believed when others doubted. She never gave up. She was a point of light in our darkened night."

Susan Osborn
The Center School, Highland Park
"Susan has extraordinary patience and compassion."

Chris Reagan
Branchburg Central Middle School, Branchburg
"Chris was my daughter's teacher for one year, but in that one year he was outstanding."

Sharon Strichek
The Midland School, North Branch
"Sharon is an angel/advocate in disguise."

Sue Routon
F.L. Walter School, Lumberton
"My son does whatever she requests. A child knows!"

NEW MEXICO

Gene Winn •
Belen High School, Belen
"Mr. Winn is a teacher who sees his students' capabilities. He believes in all his students."

NORTH DAKOTA

Sharon Olson
Anne Carlsen Center for Children, Jamestown
"She has a charismatic personality that radiates to all around her."

PENNSYLVANIA

Joanne Boyer •
New Eagle Elementary School, Wayne
"Our family has been so lucky to have someone so special help my son navigate his way through education."

Have a special teacher you want to nominate for next year?

Send nominations to:
EP Magazine
Attn: School Nominations
65 East Route 4
River Edge, NJ 07661

or email:
epedit@aol.com

SOUTH DAKOTA

Barb Halverson
Terry Redlin Elementary, Sioux Falls
"Barb is a selfless individual who truly loves her job and that comes through in the love she shows the children."

TEXAS

Laura Hamby •
Idalou
"Miss Hamby was a savior for our son!"

Stacie Hanson •
Jasper
"Stacie has made remarkable progress with my daughter, from educational, medical and personal standpoints."

Susan Wright •
Few Primary School, Jasper
"Susan is a fantastic teacher who is well organized and very professional. She really speaks up for her students' rights."

Maggie Robinson •
Few Primary School, Jasper
"Maggie is a quiet yet effective teacher. She really knows how to get the shyest student involved."

Sissy Rawson •
Few Primary School, Jasper
"Sissy loves to challenge her students. She does lots of higher level things even with inclusion students."

BEST COPY AVAILABLE

1003

TEACHERS OF THE YEAR

Elaine Deen *
FEW PRIMARY SCHOOL,
JASPER
"Mrs. Deen is very nurturing. She believes each child can be successful."

Tara Sells *
FEW PRIMARY SCHOOL,
JASPER
"Tara is so energetic! She believes in getting parents involved with their children. She made sure Jordan was included in everything!"

Becca Dougherty *
PARNELL ELEMENTARY,
JASPER
"Becca is one of the most loving teachers in the school district. She believes in her students. She really goes the extra mile."

UTAH

Carolyn Kwalick
SCHOOL FOR THE DEAF AND BLIND, OGDEN
"My daughter's life has been greatly enriched by Carolyn's class. I don't know how she does it but she is wonderful."

VERMONT

Jeanine Morelli
NEWPORT CITY ELEMENTARY SCHOOL, NEWPORT
"Jeanine has mastered the idea of inclusion in her classroom. The children feel good about themselves and feel as though they truly belong."

WASHINGTON

Dianne Conley
RIVERSIDE ELEMENTARY,
CHATTAROY
"Dianne Conley is quietly dignified with a heart built out of love. She is a nurturer to the children that teaches the parents and caregivers as well."

WISCONSIN

John Casper *
WEST MIDDLETON SCHOOL,
MIDDLETON
"Without John's perseverence, I fear my son would still not be successful."

Gigi Lombard
LAKELAND SCHOOL,
ELKHORN
"Gigi can make the most stressful and tedious jobs fun for the kids. She has made a huge impact on our lives."

Have a school you want to nominate for next year's school of the year?

Send nominations to:
EP Magazine
Attn: School Nominations
65 East Route 4
River Edge, NJ 07661

or email:
epedit@aol.com

BEST COPY AVAILABLE

REACHING UPWARD

AT THE EVERGREEN CENTER, we believe in learning as a means to personal independence. Combining school and community residence programs, The Evergreen Center creates an individual education program that helps each student become a part of the community.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631
Serving students with developmental, medical and behavioral needs since 1981.

Circle #43 or visit www.eparent.com/adinfo

BLADDER CONTROL PRODUCTS

Snuggems
HUGGIES Supreme
Pull-Ups
GoodNites

Call for your free incontinence products catalog and receive a FREE $25 gift* with your first order

DMP DURALINE
1-800-654-3376
www.dmponline.com
* Offer expires December 31, 2002. Available only to new customers, with a cash or credit card purchase over $35. Not valid with other offers. $25 gift is not pictured above.
10662

Circle #39 or visit www.eparent.com/adinfo

1004

continued from page 25

systemic lupus erythematosus, in her class, wrote a book about Scott's experience which was recently published. Valerie Lundin organized a special education talent show in Florida, which is now a yearly event.

Including special needs students in the general education classroom is not an easy task, since different learning programs are used simultaneously; however, some teachers do this proudly. Donald Brubaker of New Jersey has always made sure that Kelly Stout, who has spastic quadreplegia cerebral palsy, is an integral part of the student body. "From skating with her at a school roller skating party to riding on the back of her power wheelchair, he has always found a way to make her feel special," says mom Joyce.

Gene Winn of New Mexico, a vocational teacher, always uses positive encouragement with all of his students. Rudy, who has cerebral palsy, has never been limited in his participation in class or in outside activities.

Teachers who reach out and touch students with their insight and generosity not only help the children, but the parents as well. They get to know the family and the environment in which they live in order to fully grasp the child's viewpoint and understand behavioral problems.

When Karin Swenson of South Dakota had another baby, her daughter Sonja had trouble dealing with the change. It was Barb Halvorson, Sonja's teacher, who brought her out of her shell. Behavior problems in Sonja arose, "but Barb helped her focus on the positives of being a big sister," says Karin.

Emily Thatcher of Iowa knew well in advance that she was getting a new student, Justine Dillavou, in her classroom. Before the actual move, Ms. Thatcher made special trips to Justine's old school to acquaint herself with the program, and put pictures of Justine in her own classroom to prepare her other students for a new classmate.

Teachers must understand that it is possible for a child to learn, and they must make the child understand that as well. They must set high expectations, but never so high that the child cannot meet them.

Jeanne Clapper believes that Lydia Shields of Massachusetts has had a tremendous impact on her daughter Stephanie. "Mrs. Shields has seen to it that Stephanie be accountable for her actions, both

continued on page 30

R.E.A.L. Design Introduces VIVO™
The New Multi-Therapy Pony

Children will love VIVO, the playful, spirited little pony with the head that bounces when moved and a colorful beaded tail. Parents and therapists will appreciate the valuable skills children gain by playing on VIVO because it functions as a balance rocker or gait trainer by simply interchanging the legs which snap on and off easily. As a rocking horse, VIVO promotes balance reaction skills and upper body postural development. As a gait trainer, it provides incentive for a child to learn ambulation skills. The soft upholstered seat back, with molded laterals, is height adjustable to position children comfortably and securely for rocking or learning to walk. Accessories are available for adapting VIVO to a child's positioning needs.

R.E.A.L. DESIGN 1.800.696.7041 Fax: 1.315.429.3071
www.realdesigninc.com

Circle #74 or visit www.eparent.com/adinfo

continued from page 29

positive and negative. She has never accepted mediocrity from Stephanie. She expects that she can learn, and sees to it that she does."

"At a time when my son felt he could do nothing right and was struggling to just make it through lunchtime in the cafeteria without getting in trouble, it was Mrs. Taylor who saw Jon's musical talent and used it to help him achieve success," says Jane Frederick of Georgia teacher Hilda Taylor.

These selfless people work wonders.

For Cindy Cotter of Florida, Debby Jones has been like a member of the family. Her three children, Barbara, Chris and Billie Rebecca, all have disabilities, and Mrs. Jones has helped each of them. "She saw potential in them that others were unwilling to see," says Cindy. "She has a way with the kids. Autistic children don't always take to other people well, but my daughter Billie Rebecca does extremely well with Mrs. Jones."

These selfless people work wonders with children who have trouble learning. They have calmed fears and dried teary eyes, helped with future planning and taught independence. In a world that can be cruel to people with disabilities, it is teachers like these who guide them through it.

Alan Bloom has been struggling to find an appropriate educational program to accommodate his daughter Emma. "She is who she is, and we need to do everything we can to help her adjust to the world—and, at times, to help the world adjust to her—so that she can grow up to be happy. That is our #1 mission, and thanks to Joan Bregy of Massachusetts, we feel for the first time like that's a realistic goal."

Mark and Nicole Schmidt of North Dakota feel blessed to have Sharon Olson in their lives, and especially in the lives of their twin boys. To her and to all of the nominees, the Schmidts write, "Thank you for your hard work, dedication, love and selfless hours of special needs teaching. Our children love you and so do we."

Berkshire Meadows

Nestled in the serene beauty of Western Massachusetts' Berkshire Hills, Berkshire Meadows offers a comprehensive, integrated year-round residential program for children, adolescents and young adults who are severely developmentally delayed and may be multiply disabled.

We help our population become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement, and support. We believe that all people, no matter how severe their disabilities, should be given the opportunity to achieve their maximum potential.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523, Ext. 14
berkshiremeadows.org

Circle #27 or visit www.eparent.com/adinfo

BEST COPY AVAILABLE

Get-A-Round Gait Trainer

Freedom Designs, Inc. is proud to introduce the new Get-A-Round Gait Trainer. The Get-A-Round offers a "fresh new look" to the gait trainer market. Two sizes are available: small and medium. The Get-A-Round boasts multi adjustments for different functional needs, along with many frame and fabric color choices. The Get-A-Round promotes versatility and function with style.

FREEDOM DESIGNS
INCORPORATED ®

MULTI-FUNCTIONAL CASTER

NOTE: Caster Fork Swivel Lock
- L- Caster Lock
- R- Caster Ratchet (One Way Roll)
- F- Caster Free Wheel

2241 Madera Rd., Simi Valley, CA 93065 USA • (805) 582-0077 • (800) 331-8551 • Website: www.freedomdesigns.com

BEST COPY AVAILABLE

Circle #44 or visit www.eparent.com/adinfo

1007

EDUCATION 2002

TWINS TRANSITION AND LEAVE BEHIND A CHANGED SCHOOL SYSTEM IN THEIR WAKE

By Laura Apel

Alba and Anastasia Somoza will be two of the thousands of freshmen entering the college graduating class of 2006, but this achievement did not come easily for them, their family, or the New York City Board of Education.

The twin girls were both born with quadriplegia cerebral palsy, and because of this no one expected them even to earn a high school diploma. However, this past June the girls graduated as honor roll students from Manhattan's "School of the Future." Now they head off to two of the country's top colleges: Alba to Queens College in New York City and Anastasia to Georgetown University in Washington, DC.

> In a nationally televised town hall meeting that year, Anastasia Somoza appealed to then-president Bill Clinton as well as the New York City school system, asking that she, as well as her sister Alba (the more severely disabled of the two), be allowed to learn in regular classes.

Many parents of children with disabilities spend a great deal of time considering the academic options for their children after high school. More and more parents and students are utilizing schools that are solely devoted to those with learning and physical disabilities, but many families neglect to consider the possibility that their children will be able to live and thrive at a regular four-year college or university.

Every situation is unique to a particular student and family, but Alba and Anastasia have proven that just because something appears to be beyond their capabilities does not meant that it truly is, but instead that it has simply not yet been tested. They have faced a challenge at each level of their academic lives so far and come away among the top students entering college this year, proving that they have deserved every success they have accumulated.

EP Magazine has already chronicled the Somoza family's many hardships and battles to receive proper treatment within the public school system and the medical community (May, 1996). Now, six years later, Alba and Anastasia have proven that it was worth the effort.

Alba and Anastasia's mother, Mary, began her battle with the New York City school system in 1993, asking for the inclusion of her daughters into the mainstream program at P.S. 234. In a nationally televised town hall meeting that year, Anastasia Somoza appealed to then-president Bill Clinton as well as the New York City school system, asking that she, as well as her sister Alba (the more severely disabled of the two), be allowed to learn in regular classes.

The Somoza family succeeded in their quest and the girls were mainstreamed, making Alba the first significantly disabled student to be fully integrated into the New York City

> Filled with a number of different emotions ranging from excitement to intimidation, the girls and their family are looking forward to the new adventure…

Public Schools. The girls faced another challenge three years later when Mary found that she now needed to struggle in order to send her daughters to District 2's "School of the Future" junior high school in 1996.

Mary saw the technologically advanced, junior high/high school as the ideal place for her daughters, especially Alba, as she is dependent on a computer for her communication. Placement there would also obviate the girls' need for another transition from junior high to high school levels.

The school district estimated that the cost of creating the appropriate facilities for the girls, mainly wheelchair accessibility, would be more than $1.2 million dollars. Somoza found the estimate excessive and began another battle in the name of her daughters' rights. With the help of the Eastern Paralyzed Veterans' Association and the New York City Lawyers in the Public Interest, Mary prepared her own report. This finding put the cost at $15,000.

The report forced the school administration to back down, and the girls were enrolled at the "School of the Future." There, they experienced many academic successes but are nevertheless eagerly anticipating their transition to college. Filled with a number of different emotions ranging from excitement to intimidation, the girls and their family are looking forward to the new adventure but feel, as Mary Somoza explained, that it is nevertheless "a daunting time."

continued on page 34

Top: Anastasia making her way in her graduation procession.

Above: Anastasia and Alba proudly converse with former president Bill Clinton.

BEST COPY AVAILABLE

1009

The BEST strollers in the WORLD!
by Baby Jogger
Our Special Needs strollers are lightweight, easy to fold, and a joy to push...
www.bábyjog

Circle #83 or visit www.eparent.com/adinfo

Innisfree

Since 1971 Innisfree has offered residential and day services in an environment that fosters interdependence, creativity and respect. At the boundary of Virginia's Shenandoah National Park, it combines a low-stress rural lifestyle with access to excellent health care, cultural and social activities in nearby Charlottesville.

5505 Walnut Level Road • Crozet, Virginia 22932 • 434-823-5400
Web: www.avenue.org/innisfree • E-mail: innisfreevillage@prodigy.net

Circle #53 or visit www.eparent.com/adinfo

TWINS TRANSITION

continued from page 33

Both girls have already begun their studies at their respective schools, as they have each taken part in summer programs and events. Alba will commute to Queens College from her family's home in New York City. She is currently making arrangements with the school's disability coordinator to accommodate her needs, which Mary Somoza will no doubt ensure are met. Alba is undeclared as to her major at this time

WHEN DETERMINATION WINS

Mary Somoza described an experience that Anastasia recently had while on a summer nature retreat at Georgetown with some of her classmates. In an attempt to create relationships and bonds among the freshman class, the students took part in exercises including mountain climbing and rope bridges in Virginia.

A quadriplegic, Anastasia faced the mountain in her wheel chair and informed her peers that she would be waiting at the bottom. To her surprise, her decision was not accepted by her classmates and friends, which included three members of the Division One universities football team. Together, the teammates carried Anastasia and her chair all the way up the mountain. When they reached the top and approached the rope course ahead, those around her realized that this time she would wait behind, as the rope would only allow for one person at a time in single file.

However, Anastasia decided to get up from her chair and walk across the bridge. To help with her balance, which is impeded by the cerebral palsy, the football players guided her, and thirty minutes later she was across and received with a sea of cheering and smiles. The end of the journey came in the form of a rope drop down the mountain in what Anastasia described to her mother as the most "awesome" thing she had ever done. Shortly after the event, the students wrote about their experiences that day and many chose to comment on Anastasia, what she had done, and how they were now awakened to how much a person could truly overcome.

BEST COPY AVAILABLE

> Excited to hear all about her daughter's time there, she instead was answered with the generic college-student-to-mother axiom, "Listen Mom, I have to go now; my friends are waiting. I'll call you later!"

but may pursue her interest in art as her study there progresses.

Anastasia also began her activities at Georgetown University this summer, but will move down permanently this fall with an aide. Also undeclared as of yet, Anastasia has expressed an interest in political science and may concentrate on it as her major in the future.

Alba, Anastasia, their mother Mary, father Gerardo, older brother Oliver and younger sister Gabriella are all excited and concerned for the twins as they leave their home for the first time, transition to new schools, and face life apart from one another – something they have never before experienced. Their collective hopes for this new adjustment are that the girls will each find in their college educations all that every other incoming freshman has the opportunity to experience.

Although the twins succeeded academically at the high school level, the social aspect of their time there was far less fulfilling. Mary's desire for her two daughters is that they will find the open-mindedness and tolerance in their peers at college that are so often absent from the thoughts of the average high school student. All she wants for her daughters, all she has ever wanted for them, is for them to be given the opportunity to have access to everything that others have received so freely.

All mothers are apprehensive about sending their children to college and being away from them for the first time. Because of her daughters' conditions, Mary Somoza is finding these feelings occurring at a much greater level. Nevertheless, her fears were lessened and replaced with another emotion when she called Anastasia during her recent stay at Georgetown. Excited to hear all about her daughter's time there, she instead was answered with the generic college-student-to-mother axiom, "Listen Mom, I have to go now; my friends are waiting. I'll call you later!" EP

SAVE Up To **50%**
On Youth Briefs

GoodNites
GoodNites
GoodNites

We sell and distribute incontinent youth products at
DISCOUNT PRICES!

As a service to our customers, we offer **FREE SAMPLES** of disposable youth briefs and pull ups.

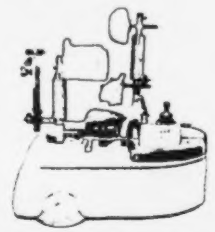
Save up to 50%

Call **1 800 777 1111** 24Hrs
WOODBURY PRODUCTS, INC.
Order online at: **www.woodburyproducts.com**

Circle #90 or visit www.eparent.com/adinfo

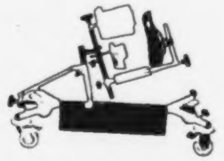
Early Childhood Mobility
Mini Go-Bot's

Century Stander


Stanford Standard

Note: Standing frames work with either Go-Bot

Yellow Go-Bot


GB-I Gait Trainer
(can be customized)

Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com

Circle #54 or visit www.eparent.com/adinfo

EDUCATION 2002

HIGHER EDUCATION OPTIONS FOR YOUNG ADULTS WITH LEARNING DISABILITIES

by Carolyn O. Cantu, MS, OTR

"There are truly opportunities to achieve the dream of a college education [for students with disabilities]," Deborah Brodbeck, President of Beacon College, Leesburg, FL.

Two schools have uniquely positioned themselves to help challenged students and their families achieve a college education. They are Beacon College in Leesburg, FL, and Landmark College in Putney, VT.

Every fall semester, high school seniors and their parents experience excitement and anxiety as they make decisions regarding jobs or colleges. For students with learning disabilities, this season adds one more hurdle to the list of challenges that has grown during the past 12 school years. Often, young adults with learning disabilities have average to well-above-average intelligence and wish to continue their education. However, there are questions to be answered: What choices are there? What support can I/my child expect? Who has experienced satisfaction in this process?

Beacon College and Landmark College are two institutions that have provided answers, along with some very satisfied students and parents.

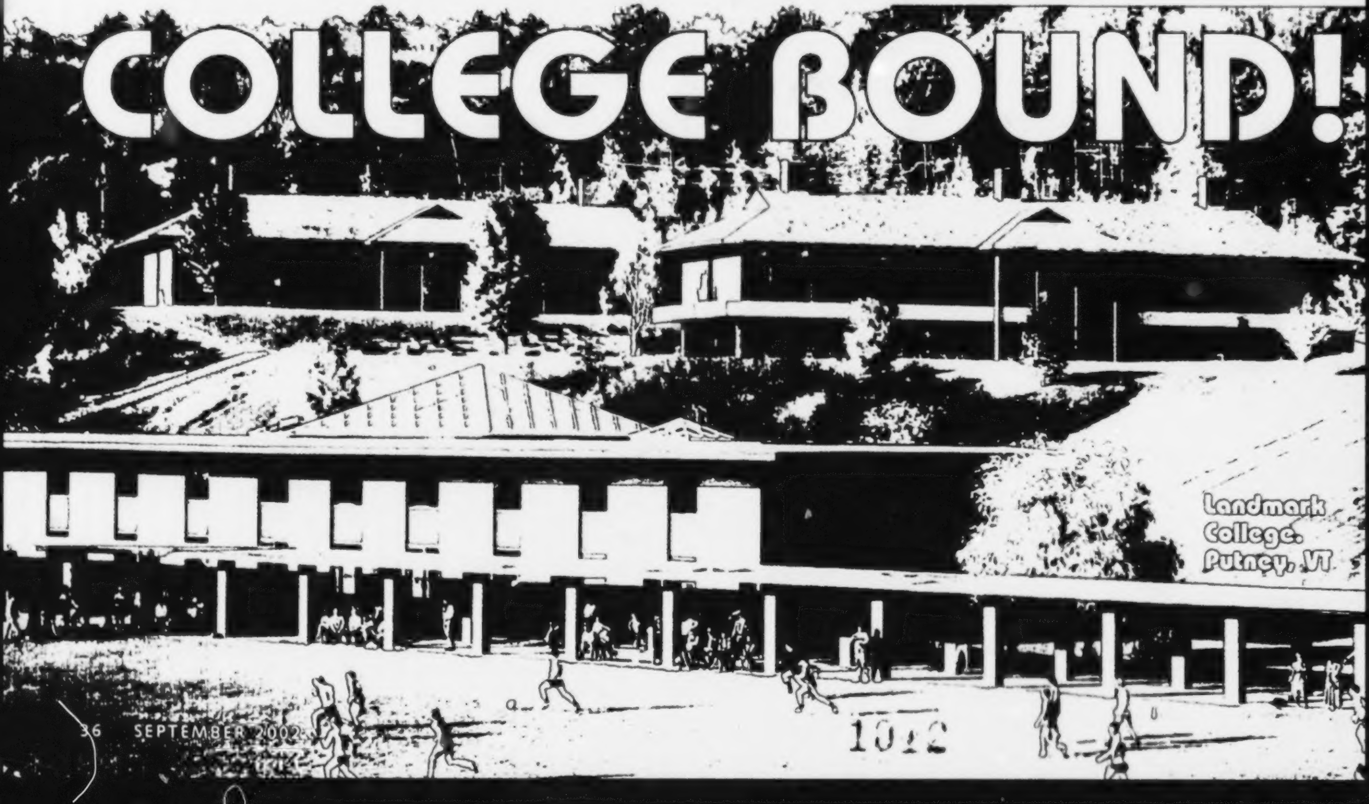
Beacon College, Leesburg, FL:

Located in Leesburg, FL, Beacon College was started by parents of teens with learning disabilities. Presently, it has about 80 students, each following a customized plan of study based on their strengths and needs. The primary disability that allows for admission is a learning disability followed by a physical disability, if relevant to the applying student.

Licensed by the Commission for Independent Education Colleges and Universities, Beacon awards Associate in Arts and Bachelor of Arts degrees in both human services and liberal arts. The school is also a candidate for accreditation by the Southern Association of Colleges and Schools (SACS) this October.

Beacon boasts a Main Street campus that allows students easy access to places for social gathering. Living accommodations are provided in apartments separate from the school campus and special transportation is available to take students to and from classes.

Community based field placements offer hands-on, practical work experience in public and community services.


COLLEGE BOUND!

Landmark College, Putney, VT

Placements are in the town of Leesburg and often lead to more permanent employment.

President Deborah Brodbeck believes that Beacon's cornerstone is their mentoring program. Students are assisted by mentors who help them determine their own realistic goals, discover which learning techniques work best for them in varied situations, enhance their abilities and explore their potential. "Students come into their own academically here" President Brodbeck declares.

Students also have access to tutors, psychologists and counselors who can help them discover who they are as learners and develop their own individualized strategy for learning. This development of self-awareness and cognitive strengths, as well as the acquired perception of realistic views and limitations, is influential in making future career choices.

The graduate success rate is impressive. As of December 2000, 100 percent of Beacon College graduates went on to higher learning or were hired directly out of school. The statistics for May 2001 showed that 90 percent of the graduates did the same.

Landmark College. Putney, VT:

Founded in 1983, Landmark had students enrolled for classes by 1985. Over the years the enrollment has grown to 380 with the expectation of up to 450 students in the future.

Landmark's mission is to provide a rigorous educational program for students with dyslexia, ADHD and special learning disabilities. The two-year program ensures a self-empowerment that is based on the development of academic strengths and the internalization of a positive self-esteem.

Admission to the college requires documented proof of a learning disability, dyslexia or ADHD from the secondary school's educational psychologist. Students are supported through each phase of the admission, transition and adjustment periods while attending Landmark. Curriculums are structured, defined and developed to ensure measurable results in the students' success during their initial higher education experience, and faculty understand that course of action.

Students live in residence halls supported by development professionals who live on each floor. This arrangement reinforces an integrated approach to college life that teaches students to balance social and academic experiences, while also providing a sense of community.

Instructor Mike Hutcheson describes Landmark as a place where "Our students aren't empty vessels that we fill with information. We look at an individual, assess strengths and weaknesses and develop methods that work for each student."

continued on page 38

MARGUERITE: A CASE OF PERSEVERANCE

In 1993, fifth grader Marguerite Annis lived the life of a typical little girl. Suddenly, this lively ten year old developed persistent migraine headaches, blurred vision and projectile vomiting that could not be relieved with medicine. A MRI detected a tumor that had grown within the optic chiasm, impairing her vision and pressing on the hypothalamus gland. Pressure was moving toward the brain stem.

After many visits to the doctor and numerous tests, Mr. and Mrs. Annis took her to the Mayo Clinic in Rochester, MN. The tumor was removed and the first of six revised shunts was implanted. Although Marguerite's strength, coordination and ability to walk were not initially affected, her vision was impaired. Unfortunately, by the time she was 14 the tumor had grown back.

This time the doctor performed more aggressive surgery. He removed the tumor, keeping her personality intact, but sacrificing her short-term memory and vision acuity. In the following summer convulsive seizures started occurring. After frequent adjustments due to allergies, the medications were finally regulated. Ataxia accompanied by seizures developed, causing Marguerite to walk with an unsteady, weakly balanced gait that required the use of a cane. Physical therapy focused on walking, coordination and balance. In the midst of all this, she was living with diabetes insipidus.

By the tenth grade, Marguerite was falling behind in her studies. The public school's special education program arranged for her to have extra time to take tests and transfer to and from classes. "A closed door was not going to stop me!" Marguerite exclaimed as she described trying to pass through a closed door while negotiating both a walker and back pack during her years in high school.

After her sophomore year, she left the area high school and attended a school for children with special needs. In a wheelchair, Marguerite returned to the area high school for her senior year and graduated among her peers.

A crucial time was upon her. Where do I go? What do I do after high school? A special guidance counselor suggested Beacon College or Landmark College.

Now she is a junior at Beacon College, working towards a bachelor's degree in human services and hoping to someday further her studies. Marguerite continues to deal with the physical and mental impairments caused by extensive neurosurgery and seizures. Nevertheless, the determination and courage that propelled her towards achieving her dream of attending an institute of higher learning remains with her as the guiding force of her many successes. One closed door at the high school level did not stop her. Many more students are finding that they too have the same opportunities.

BEST COPY AVAILABLE

continued from page 37

REFERENCES FOR PARENTS

Beacon College
105 E. Main Street/ Leesburg, Florida 34748
Tel: (352) 787-7660 Email: beacon4@mpinet.net
Website: http://www.sundial.net/beacon
or www.beaconcollege.edu

Landmark College
River Road South
PO Box# 820/ Putney, Vermont 05346
Tel: Office of Admissions: (802) 387-6718
Website: http//www.landmarkcollege.org

Fernando H. Shahbaznia, Associate Vice President of Institutional Advancement for Landmark College, emphasizes that this experience is not a "quick fix" toward higher learning. If a student demonstrates tenacity, hunger and a driving will to learn within the sustained process of learning, "a radical metamorphosis in achievement will occur."

He equates attending Landmark College with being surrounded by 380 mirrors, because students see themselves in what others are doing. The peer support and relationships that develop are lifelong and the network of alumni reaches through generations. "The borders of disability are dissolved and students are able to reach higher and higher for the keys to open doors of opportunity."

Both Beacon College and Landmark College are unique in that they exclusively admit students with learning disabilities. These institutions are dedicated to providing a supportive but vigorous atmosphere for learning at this level. Students develop a strong sense of self-esteem, self-awareness and lifelong learning or work strategies. Both programs present a holistic approach to learning in higher education and emphasize the "goodness of fit" with cognitive strengths usually leading to employment or higher education for students with learning disabilities. ◆

Carolyn O. Cantu, MS, OTR, is a licensed pediatric occupational therapist and educator who has practiced and taught all over the world for 32 years. Most recently, she was a pediatric therapist and clinical educator for the Infant Parent Program, Austin, TX.

CHILEDA INSTITUTE

Educators for youth with developmental disabilities. Residential treatment center provides complete training & intensive therapy for children with severe mental & physical disabilities, closed head injuries & challenging behaviors. Founded 1973.
- Intensive
- Progressive
- Specialized

founded in 1973

Chileda Institute
1020 Mississippi Street • La Crosse, WI 54601
608-782-6480 • Fax: 608-782-6482
Web site: www.chileda.org

Circle #31 or visit www.eparent.com/adinfo

Crystal Springs School
A PROGRAM OF THE
Institute for Developmental Diabilities, Inc.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.
- 30 acre campus in Southeastern Massachusetts, close to Boston, Cape Cod, Providence and Newport, RI.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, Including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availablity.
- Licensed by the MA Office of Child Care Services.
- Approved by the MA Department of Education.
- Member of the MA Association of Approved Private Schools.

For information, Please Call Our Admissions Coordinator:
1-800-840-8087 (508) 644-3101 Ext: 375

Circle #37or visit www.eparent.com/adinfo

TIGER

The Tiger from R82 is a versatile dependent tilt-in-space push-chair that can handle the individual seating requirements of almost any child with special needs. The seat easily reclines from an upright to a horizontal position allowing your child to be active or relax. The seat width, depth, and back height adjust to expand as your child grows. The reversible seat allows a caregiver to maintain eye contact with the child at all times. The seat easily removes from the base for storage and transport. The cover easily removes for laundering.

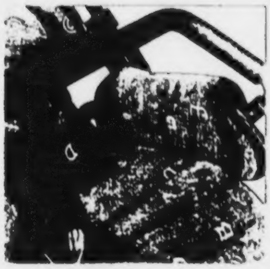
The Tiger is available in two sizes and four fabric selections. Weight capacity for the size 1 is 77 lbs., and 110 lbs. for the size 2. The Tiger seating system can be utilized on several of our mobility frames. Optional accessories include a variety of headrests, harnesses, straps, swing-away lateral supports, and more.

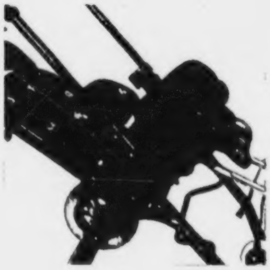
CALL SNUG SEAT NOW FOR YOUR FREE CATALOG

1-800-336-7684

SNUG SEAT®

ircle #78 or visit www.eparent.com/adinfo





1015

BEST COPY AVAILABLE

EDUCATION 2002

RIDGEWAY

A VERY SPECIAL SCHOOL

When they first enter the main building, potential students and teacher applicants speak of a "different" feeling that pervades the Ridgeway School in Severn, MD.

When asked to describe this feeling, current teachers, administrators and parents have difficulty articulating what is an essential part of this nationally renowned cluster school in suburban Washington, DC. Asked to describe Ridgeway in one word, administrators say "caring." Faculty say "commitment." Parents say "community."

EP Magazine calls it "trust."

Taken together with its academic and athletic achievements, programs for gifted and challenged children and its overall level of excellence, this 630-pupil complex is EP Magazine's Educational Institute of the Year.

Headed by Duane Arbogast, Ridgeway School is housed in a two-year-old building, the planned capacity of which is already being outgrown. This fall, the elementary school, levels kindergarten through fifth grade, is supporting 100 students with disabilities, 25 of whom have severe or multiple disabilities.

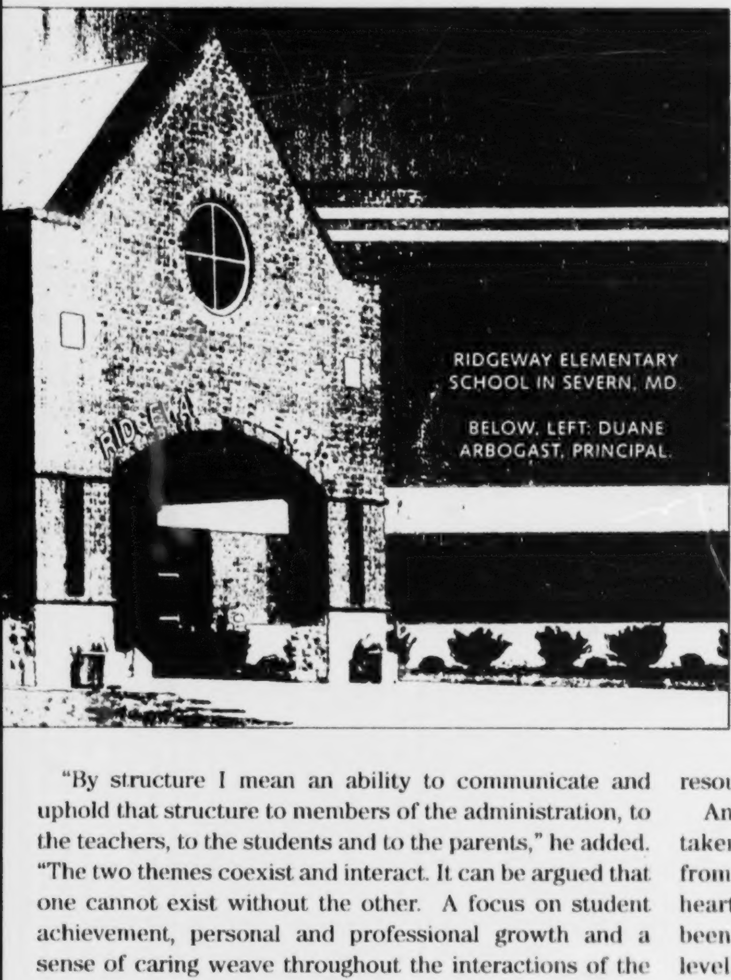
Starting in homeroom, the school attempts to integrate all students. "We want everyone to feel part of the student body," says Arbogast. "We structure the school schedule around providing students with disabilities the best chance to be included."

Where possible, students with disabilities take the same classes as other students. "There is a climate of learning and accountability that includes every student," Arbogast says. "In short, we hold students with disabilities accountable just like any other student. In the process, we are able to get the support of the entire student body. They pitch in and foster this climate of participation and acceptance. The process is a learning experience for them as well."

Arbogast advises other educators in similar situations to focus on culture and structure. "By culture I mean a philosophy where special education is given a definite role within the overall structure," he said.

BEST COPY AVAILABLE

SCHOOL



RIDGEWAY ELEMENTARY SCHOOL IN SEVERN, MD.

BELOW, LEFT: DUANE ARBOGAST, PRINCIPAL.

"By structure I mean an ability to communicate and uphold that structure to members of the administration, to the teachers, to the students and to the parents," he added. "The two themes coexist and interact. It can be argued that one cannot exist without the other. A focus on student achievement, personal and professional growth and a sense of caring weave throughout the interactions of the daily life at Ridgeway."

"Children are to be treated as if they were our own," said Michele Overend, special education teacher. "We try to create an individual program for every student. Educational and placement decisions are based on how we would want our own children treated."

This sense of individualized training is extended to every student. Consequently, there is a high sense of trust from the community, says Leslie Twohig, a parent volunteer. "Parents of children without disabilities know that the school also focuses on those with exceptional talent," she said. "We all know the school focuses on the individual student and our children are getting a high level of education. This is a reason that such a great well of trust exists amongst us all."

Trust is a central tenet of the professional learning community. Through the shared vision of service to children and professional development, the staff at Ridgeway actively works to improve every facet of the program through reflection and critical analysis. Teachers are encouraged to take instructional risks in a supportive environment. With student growth and achievement as the goal, teachers implement new strategies, practice and revise instruction and reflect with colleagues.

Part of the school's success is the high degree of professionalism and dedication exhibited by the staff. Because they are part of the entire process, the teachers are committed to the structure and philosophy of Ridgeway.

"We like to think that they are 99 percent supportive of the programs and 100 percent involved in making it work," said Overend.

Arbogast said the school tries to create an individual program that works best for the child. Sometimes an entire family could be involved and requires the school to look at family issues and provide support, whether the issue is physical health, emotional health or guidance.

"Children with disabilities come from all over the county and parents even 'parachute' into the district to go to Ridgeway," Arbogast said.

Ridgeway also sometimes takes responsibility to educate the entire family through verbal and written communication. To do this, it must mobilize resources in the community to provide support for families.

An example of this vision is embodied in the actions taken when a family enrolled in April. The family was from Texas but spoke no English. The two-year-old had heart problems and Down syndrome. The 13-year-old had been retained in two grades and read at a first grade level. The nine-year-old had only limited English. The staff at Ridgeway was able to coordinate health and educational services for the two-year-old and provide age-appropriate instructional settings for the nine- and 13-year-old children.

"We like to think of ourselves as a safety valve for many local schools," Arbogast said. "We accept many students whose parents have fought with their school boards and finally they all agree that the child would be best at Ridgeway."

As a total educational facility, Ridgeway represents the best in American education and is extremely worthy of the award it will receive in October at the World Congress & Exposition on Disabilities. ■

BEST COPY AVAILABLE

EDUCATION 2002

Enhancing Inclusion with the Navy Run, Jump 'n' Throw

Joseph Valenzano, Jr., President, Exceptional Parent Magazine
Jim Santos, President, Navy Run, Jump 'n' Throw

This year, schools in California, Missouri and Maryland joined more than 22,000 other institutions conducting the Navy's Run, Jump 'n' Throw. These schools held programs geared for special needs students, thereby providing inclusion through sports in three exciting formats. Each event was successful in providing a fun, challenging and rewarding program for students with a disability.

In February 2002, Mr. Lee Webb, Head Track Coach and Adapted Physical Education teacher at the James Logan High School in Union City, CA, conducted the Navy Run, Jump 'n' Throw Olympic Clinic, which is now recognized as the largest track clinic for students in the United States. Athletes from the Special Olympics played an important role in this regional event which attracted 22 Olympic athletes and more than 2,000 students. Children from ages 8-18 were paired with students with a developmental disability, and as partners, they participated in the clinic.

In April of 2002 Mr. Webb was the Meet Director for the Navy Run, Jump 'n' Throw Track and Field Invitational Meet, established for high school athletes in northern California. The Invitational provided events in which Special Olympics athletes with a developmental or physical disability could represent their high school and compete in the same programs as their non-disabled peers. This two-day competition attracted more than 2,000 students.

In May, the St. Louis Special School District hosted the Navy Run, Jump 'n' Throw Sports Day. Directed by Ms. Jackie Rahm, Sports Director for the St. Louis County Special Olympics, this inclusive program featured the senior class of Hazelwood West High School as partners, officials and volunteers.

May 23, 2002 presented a wonderful opportunity for elementary students representing Ridgeway Elementary School, Marley Elementary, Jones Elementary and Meade Elementary at the Navy Run, Jump 'n' Throw Ridgeway Elementary Invitational in Severn, Maryland. A warm sun smiled on the opening ceremonies provided by the United States Navy Color Guard of Washington,

BEST COPY AVAILABLE

Students prepare for the big race

Left: A team of students in matching shirts head off for their event.

Below: Participants take a break from the busy day to smile for the camera.

Joseph M. Valenzano, Jr., President, CEO and Publisher of EP Magazine, poses with the United States Navy Color Guard of Washington, DC.

DC. More than 175 students took part in four different events during this three-hour invitational. To add to the occasion, Jim Santos presented Joseph M. Valenzano, Jr., President, CEO and Publisher of EP Magazine, the first Navy Run, Jump 'n' Throw President's Award for his continual support and promotion of the Navy RJT program.

This flagship event was put together by the Partners for Success of Anne Arundel County (a family support group for special needs children), Special Olympics Anne Arundel County and Special Olympics Maryland, who worked together to support the Ridgeway Elementary Invitational.

Why is the Ridgeway Elementary School the flagship for the Navy Run, Jump 'n' Throw? The answer is simple: because so many people were involved in making it an outstanding event. With more than 1,000 people representing students, Special Olympics, families, staff, administrators, Partners for Success and Navy Run, Jump 'n' Throw in attendance, this illustrates the best inclusion practices on or off the playing field. Sports just happen to be the vehicle for this inclusion activity.

Because the Navy RJT program is so unique, schools may choose to use the program in a variety of teaching and activities that suit the needs of their students and staff. It also may be the only time a student with a severe developmental disability will have a chance to wear a tee shirt representing his or her school, and play on the same team as non-disabled friends. Public and private schools throughout the United States are benefiting from the Navy Run, Jump 'n' Throw with a variety of opportunities for students, staff and teachers to learn about sports and each other. EP

To register to receive the Navy Run, Jump 'n' Throw Sports Guide at no charge, visit: http://www.runjumpnthrow.org. If you have further questions about any of these events, call Frank Kolarek, Vice President, Navy Run, Jump 'n' Throw at (410) 791-1023.

BEST COPY AVAILABLE

World Congress & Exposition on Disabilities

October 3-5, 2002 ◆ Orlando, Florida

EDUCATIONAL SPONSORS

Allergan, Inc.
American Academy for Cerebral Palsy
& Developmental Medicine (AACPDM)
American Academy of Pediatrics
American Association for Active Lifestyles & Fitness (AAALF)
Association of University Centers on Disabilities

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD
WCD

Over 200 Conference Sessions

Over 250 Product & Service Providers

Sports & Recreation Activity Center

Employment Pavilion

Assistive Technology Learning Center

Employment Symposium
Sponsors

MEDIA SPONSORS

Active Living magazine
Disabled Dealer of Southeast
EP (Exceptional Parent)
inMotion
New Mobility
PALAESTRA
Paraplegia News
Sports 'N Spokes
Teaching Exceptional Children
Today's Caregiver
We Media

SUPPORTING ORGANIZATIONS

AAMR
America's Athletes with Disabilities
Amputee Coalition of America
Angelman Syndrome Foundation
Autism Recovery Network
Autism Society of Florida
Council for Exceptional Children
Easter Seals
Families of S.M.A.
Family C.A.F.E.
Family Voices
Florida Alliance for Assistive Service
and Technology, Inc. (FAAST)
Florida Association
of Rehabilitation Facilities
Florida Children's Forum/Central Directory
Florida Institute for Family Involvement (FIFI)
Muscular Dystrophy Family Foundation
National Family Caregivers Association
National Multiple Sclerosis Society
National Perinatal Association
RESPECT of Florida
Southeast Disability & Business Technical
Assistance Center
Special Olympics
Spina Bifida Association of America
TASH
UCP
United Parents' Syndicate on Disabilities

1020

BEST COPY AVAILABLE

(877) 923-3976 x832 ◆ wcdinfo@wcdexpo.com ◆ www.wcdexpo.com

HAB H.A. BRUNO, LLC
EP Exceptional Parent
sigma-tau PHARMACEUTICALS, INC.
EP Foundation for Education, Inc.

Circle #91 or visit www.eparent.com/adinfo

Taking The Next Step Together

Moving forward... a new location... a whole-hearted vision

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

THE THIRD ANNUAL WORLD CONGRESS & EXPOSITION ON DISABILITIES

SHOW DATES:
Thursday, Friday & Saturday—
October 3 - 5, 2002

LOCATION:
Orange County Convention Center—
Orlando, Florida

A UNIQUE GATHERING—A Disability Conference and Trade Forum, bringing together families and professionals all under one roof. Orlando, one of the world's most popular vacation destinations, is the perfect setting for this coming together. The WCD will attract **physicians • families • direct support professionals • people with disabilities • allied health care professionals • educators • adapted physical education specialists.**

TRADE SHOW: Meet with over 250 exhibitors including product & service providers, organizations, manufacturers, retailers, home medical equipment dealers, distributors, long term care, rehabilitation and extended care facilities.

SPECIAL FEATURES

SPORTS & RECREATION ACTIVITY CENTER: Features top athletes with disabilities in basketball, tennis, rugby, soccer, track and field and more, hosted by America's Athletes with Disabilities.

EMPLOYMENT SYMPOSIUM AND PAVILION: Human resource managers will discuss career opportunities, sponsored by Florida's Agency for Workforce Innovation and the Florida Department of Education, Division of Vocational Rehabilitation Services (DVRS) and McDonald's Corporation.

ASSISTIVE TECHNOLOGY LEARNING CENTER: Produced by FAAST. Computer Stations designed for hands-on education and fun.

FAMILY, PROFESSIONAL AND GOVERNMENT ORGANIZATIONS: Meet with over 30 national and regional organizations, non-profit associations and professional societies.

CONFERENCE PROGRAM: Comprehensive, multi-disciplinary approach to education. Seminars will focus on medicine, education, family issues, advocacy, assistive technology, adapted physical education and career/employment.

- All WCD attendees can experience discussions by internationally renowned experts specializing in neurology, orthopedics, pediatrics, internal medicine, family medicine, physical medicine, epidemiology, DDS, movement disorders, mitochondrial and metabolic disorders, neonatology, seizure disorders, autism, and other disabilities and chronic conditions as well as general practitioners.
- CME and CEU accreditation, through approved accreditation institutions, will be offered for a dozen disciplines.
- Hear parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.
- An Employment Symposium produced in conjunction with Florida's Agency for Workforce Innovation and the DVRS will offer sessions for people with disabilities, their families and employers.
- Learn from special education professionals what is going on in classroom environments.
- Participate in adapted physical education activities and seminars.

EDUCATIONAL SPONSORS

Merrill Lynch

Office of Rare Diseases
National Institutes of Health

October 3-5, 2002 • WORLD CONGRESS & EXPOSITION ON DISABILITIES

Division of Vocational Rehabilitation Services (DVRS) Hosts Employment Symposium and Pavilion

Florida Department of Education

Florida's Division of Vocational Rehabilitation (DVRS) is helping to host a three-day employment symposium and pavilion to be held concurrent with the World Congress & Exposition on Disabilities (WCD) from October 3-5 at the Orange County Convention Center in Orlando, Florida.

The Symposium will feature over 50 workshops on disability issues designed to provide individuals with disabilities and their families, educators, employers, and DVRS counselors and customers a forum for information exchange. According to WCD organizers, the workshops will cover employment issues encountered "from the time a person wakes up in the morning until he or she goes to bed at night."

In addition to the basic issues of employment, speakers will discuss topics such as self-employment, mentoring, school-to-work transition, assistive technology, and national service opportunities.

DVRS is charged by both federal and state statutes with helping individuals with mental or physical disabilities that constitute or result in a substantial impediment to employment. Eligibility is based on the presence of a physical or mental impairment and a goal of employment.

Once individuals are deemed eligible, DVRS works with them to decide what type of services are necessary to overcome the impediment and how best to find either gainful employment or supported employment. Typical services might include training or retraining, school-to-work transition assistance, medical or psychological evaluation and treatment, and rehabilitation engineering or assistive technology.

Studies have shown that two out of every three people with a disability would prefer to be working and be self-sufficient. DVRS provides a hand up to self-sufficiency, not a hand out. On average, DVRS invests $2,917 per customer to assist Floridians with disabilities in overcoming barriers to employment. That investment yields an average income increase of $312,210 per customer over a 30-year work life, according to a 1999 study conducted at Florida State University. That income is then used to stimulate the economy through consumer spending and tax contributions and to reduce public spending previously used to support those Floridians with disabilities who would rather work.

For more information about the DVRS program, call (800) 451-4327 or visit the web site at http://rehabworks.org.

The WCD Employment Pavilion, also sponsored by McDonald's Corporation, will include human resource managers from dozens of companies, including local and national corporations as well as government agencies, for the purpose of discussing opportunities for those seeking employment.

we love to see you smile™

WCD EMPLOYMENT SYMPOSIUM TOPICS INCLUDE:

THURSDAY, OCTOBER 3

- Developing Quality Transition Individual Educational Plans
- Enhancing VR Services and Employment Outcomes Using AT
- Career Development Intervention for High School Students with Disabilities
- Self-Employment
- On-The-Job with Hearing Loss
- Is There Life After High School for Students with Disabilities?
- Smooth Sailing through Vocational Rehabilitation
- Reach Independence through Self Employment—A New Initiative of the Florida Division of Blind Services
- State Rehabilitation Councils Then and Now
- Public School to Post Secondary Education to Work
- Accommodating Abilities: More than Ramps & Parking Spaces
- Vocational Rehabilitation: Questions and Answers
- Supported Employment Changeover Systems
- Florida's Workforce System and how it's Changed from the Poverty Business to the Prosperity Business

FRIDAY, OCTOBER 4

- After High School: How to use all those LD Assessments for Transitioning FTRI/ Business Partnership Program
- Presidential Initiatives: Using Technology to Increase Employment of People with Disabilities
- Mentoring Programs for Students with Disabilities
- Reality-Based Partnerships with Private Industry
- Disabilities Under the Arches
- Self Determination for Improved Transition Outcomes
- Advances in Rehabilitation & Technology: Expanding Employment Options
- Smooth Sailing through Vocational Rehabilitation
- Projects with Industry...Partnering with Business for the Employment of People with Disabilities
- Addressing the Diverse Needs of Individuals with Disabilities in Disasters
- The Role of Interagency Councils in Enhancing Employment for Students with Disabilities in Transition
- Linking "O-Net" Assessment Tools to the Hot Jobs
- Development and Execution of Individualized Plans for Employment within Vocational Rehabilitation
- Supporting Individuals with Autism in Employment
- Florida's Front Door to Workforce Services
- Self Determination: Getting a Life!
- Creative Strategies for Securing Gainful Employment
- The Federal Freedom Initiative: New Framework for Disability Services and Florida's Olmstead Project
- Florida's Front Door to Workforce Services

SATURDAY, OCTOBER 5

- How to Prepare & Present a Transition Forum for High School Students
- Let Hands do the Talking: Survival Signs in the Workplace
- Florida's Survey of the Employment Needs and Goals of Individuals with Developmental Disabilities
- Help Individuals Prepare for Careers: Take a Stand for Person Centered Planning
- Florida High School/High Tech: A New Direction for Students with Disabilities
- Self Determination: So What's the Question?
- Untangling Transportation Traps
- Career Development for the 21st Century
- Job Searching
- Work Incentives and Opportunities
- Factors Affecting Successful Rehabilitation of Persons With Disabilities
- Community for All
- How the Vocal Rehabilitation Process Happens
- View from the Top: What Does a Supported Employment Agency Look Like Today?
- Florida's Workforce System and How it's Changed from the Poverty Business to the Prosperity Business
- HIV/AIDS and Employment
- National Service Opportunities for Persons with Disabilities
- Employing Individuals with Disabilities
- Florida's New Education System Structure and Other Recent Legislation: How it will Impact VR
- Florida's Front Door to Workforce Services

WCD EXHIBITORS

A.C.F. Environmental
AAMR-American Association On Mental Retardation
Able Pathways Consulting
Accessibility Services, Inc.
Acorn Stairlifts Inc.
Adaptive Dancing
Advanced Respiratory
Allen Institute
Allergan, Inc.
Alternatives for Special Kids
Altimate Medical
Amcar Motors Corp.
America's Athletes with Disabilities
American Association for Active Lifestyles & Fitness (AAALF)
Anew International
Angelman Syndrome Foundation
Anne Carlsen Center for Children
Applied Nutrition Corp.
Aquatic Access Inc.
Aurora Ministries
Autism Recovery Network
Autism Society of Florida
B Wells Promotions
Barrier Free Lifts
Best Bath Systems
Betacom Corporation
Beyond Adversity TV
BeyondHearingAids
Blue Cross Blue Shield of Florida
Bodypoint Designs Inc.
BodySense
Bunni - Steps Design Innovation and Concepts, Inc.
Bureau of Engraving & Printing
Calmoseptine, Inc.
Cambrooke Foods
Canine Companions for Independence
Carla Neumann-Hinds
Challenge Publications
Children's Medical Services
Christopher & Dana Reeve Paralysis Resource Center
Clarke Health Care
Cloister Creek
Columbia Medical
Communicating Partners Center
Communication Access Network
Concord Elevator Inc.
Continental Press/Seedling Publication
Convaid Inc.
Council for Exceptional Children
Crotched Mountain
Custom Mobility, Inc.
Cyberonics, Inc.
David Mandt & Associates
DBH Attachments, Inc.
Defense Threat Reduction Agency
Department of Defense Dependents Schools
Department of Veteran Affairs
Destiny Futurequest, Inc.
Dietary Specialties
Disabled Dealer Magazine
Disney Worldwide Services, Inc.
DMR
Dolphin Human Therapy
Downi Creations Inc.
Driving Aids Development Corp.
Drymids
Dynavox Systems LLC
Dystonia Medical Research Foundation
Easter Seals
Economic Mobility
Effective Communication Solutions, Inc.
ElDorado National
Emergency Caller Systems/Peat
English Avenue Industries
EP (Exceptional Parent) Magazine
Epilepsy Foundation
EP Foundation for Education
EP Library
Euromed Rehabilitation Center
Euro-Peds
Families of SMA
Family C.A.F.E.
Family Voices
FedEx Services
Federal Medicare Agency
Fischler Graduate School of Education
Flaghouse
Florida ADA Leadership Network
Florida Alliance for Assistive Service and Technology, Inc. (FAAST)
Florida Association of Rehabilitation Facilities
Florida Children's Forum/ Central Directory
Florida Independent Living Council
Florida Institute for Family Involvement (FIFI)
Florida Spinal Cord Injury Resource Center
Ford Motor Co.
Frank Mobility
Freedom Concepts Inc.
Freedom Vans, Inc.
Gabby's
Gemma B. Publishing, Inc.
General Motors Mobility
Genzyme
Guldmann Inc.
Harry Klitzner Company
Health South
Heartspring School
Hewlett Packard
Hoveround Corporation
Hyperbaric Therapy Center
Invacare
Island Dolphin Care, Inc.
JayJo Books, LLC
Judge Rotenberg Educational Center
KayJae Manufacturing Co., Inc.
Kinetech, Inc.
League School of Greater Boston for Asperger/ Autism Disorders
Learning Strategies, Inc.
LNR Publications
Magitek.com, LLC
McDonald's Corporation
Mead Johnson
Merrill Lynch & Co. Inc.
Metroplex Voice Computing Inc.
Mind Wing Concepts Inc.
Moving Solutions
Mulholland Positioning Systems Inc.
Multiple Sclerosis Foundation
Muscular Dystrophy Family Foundation
MyMedMart, Inc.
NASA/John F. Kennedy Space Center
National Captioning Institute
National Deaf Academy
National Disability Sports Alliance
National Family Caregivers Association
National Institutes of Health
National Multiple Sclerosis Society
National Perinatal Association
New Mobility Magazine
NewHope Generation, Inc.
NIH, Office of Equal Opportunity & Diversity Management
NISH
North Oakland Medical Centers
Nova Southeastern College of Dental Medicine
Nova Southeastern College of Optometry
Ocean Hyperbaric Neurologic Center
Office of Civil Rights, International Broadcasting Bureau
Office of Rare Diseases, NIH
P.S. I Love You! Clothing
PALAESTRA
Pathways Development Group, Inc.
Perkin Elmer Life Sciences
Permobil
Picture Me Foundation
Possibilities Foundation, Inc.
Prairie View Industries, Inc.
Prentke Romich Company
Pride Mobility Products
R.D. Equipment
Rare Disease Therapeutics, Inc.
Remedia Publications
RESPECT of Florida
Ricon/Concord
Rifton Equipment
Ross Products Division/ Abbott Laboratories
Sammons Preston
School District of Osceola County
Scooter Lift Mfg Co.
Search Beyond Adventures
Selective Testing Services, LLC
Shire US Inc.
SHS North America
Sigma Tau Pharmaceuticals, Inc.
Snug Seat
Social Security Administration, Office of Disability
Southeast Disability & Business Technical Assistance Center
Southpaw Enterprises, Inc.
Special Olympics
Sunrise Medical
SureHands Lift and Care Systems
T-Formation
TASH
Teaching Exceptional Children
Texas Neuro Rehab Center
The Autism Recovery Foundation
The Center for Discovery
The Centers for Medicare & Medicaid
The Disability Resource
The Endorphin Corporation
The Hali Project
The Liberty Motor Co Inc.
The National Neurofibromatosis Foundation, Inc.
TherAdapt Products Inc.
Time2Read
Today's Caregiver
Trac About, Inc.
UCP
United Mitochondrial Disease Foundation
United Parents' Syndicate on Disabilities
United States Mint
Universal Motion
UnumProvident
US Customs Service
US Department of Education
US Department of Energy
US Department of Justice
Vail Products Inc.
Viewpoint Mobility
Vision for Life
Volkswagen of America
W.B.Saunders/Mosby/Churchill
Wal-Mart Stores, Inc.
Walt Disney World Company
Wheelchair Getaways Inc.

Exhibitors at press time

For complete details, visit our website at www.wcdexpo.com ◇ Call: (877) 923-3976 x832 or email: wcdinfo@wcdexpo.com

EDUCATION 2002

HOW TO FIND A HIGH-QUALITY INCLUSIVE CHILD CARE PROGRAM

By Stacy Scott, M.Ed. and R.A. McWilliam, Ph.D.

The Individualizing Inclusion in Child Care model demonstration project, funded by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (Grant No. H324M980207), has developed, implemented and evaluated a model for providing high-quality inclusive child care experiences for children with disabilities aged birth through five years. Stacy Scott, M.Ed., is the project coordinator of this effort and often fields questions from parents of children with disabilities concerned with proper care for their children. The following letter lead to the writing of this article.

> ***Dear Stacy,***
> ***I have been searching for child care for my three-year-old son, Garrett. Garrett has developmental delays and sees a speech therapist. I have been able to stay at home to take care of him up until now, but my situation has changed and I must return to work full time. The specialized programs I have been referred to that would address my son's needs last for only half the day. I need full-day child care. I have visited several regular child care programs in the area but none of the staff seem to have any experience with children with delays. I am aware that many child care programs have some type of rating that indicates the quality of care provided, but how can I determine the quality of care that will be provided to my child with special needs? Do you have any suggestions?***

Finding high-quality child care is a challenge for many families—one that is exacerbated for families of children with special needs. In their efforts to find out whether their options are of high quality, families might consider quality rating systems, association accreditations, and other overall quality indicators that have been developed. But what constitutes high-quality care for typically developing children might not be high quality for children with disabilities. How can families of children with disabilities ensure their child has a high-quality inclusive child care experience?

Beyond making sure that a child's basic caregiving needs are met (e.g., feeding, diapering and a clean, safe environment), parents of children with disabilities might be worried about:

- how their child will participate in daily classroom activities with peers;
- how different professionals working with their child will coordinate their efforts in different areas (e.g., positioning and handling techniques, specialized equipment, teaching strategies); and
- how their child's developmental skills will be addressed and extended to ensure that the child is reaching his or her full potential.

The Individualizing Inclusion in Child Care model project has successfully demonstrated how to assuage some of these concerns. The model's three key components are:

- providing caregivers with a system for functional assessment and intervention planning;
- integrating related services; and
- addressing children's individualized needs within the context of classroom routines.

Families can use this model of best practices to identify the appropriateness of a child care program. Over the years, we have found it useful to think of children's needs in terms of their engagement, independence and social relationships.

How will the child participate in daily classroom activities with his or her peers?

Early childhood classrooms have a schedule of regular daily routines, which usually consists of arrival, free play, snack, circle time, centers and so on. In order to plan how individual children will participate in daily routines and activities, programs can use routines-based assessment. This assessment is a functional method for determining what a child can do and what a child needs to learn in order to participate as independently and successfully as possible in daily routines.

Routines-based assessment involves interviewing a child's

regular caregivers (i.e., parents and teachers) to identify child independence, engagement, and social competence within each daily routine. The interview results in a list of functional goals that caregivers can address in daily routines.

Through a discussion of daily routines, adults identify what a child is able to do and what skills or behaviors he or she needs to learn to participate in the most daily activities.

The value of the routines-based assessment is three-fold.

Regular caregivers identify goals. Unlike formal assessments, when an unfamiliar adult decides what skills your child needs to work on, routines-based assessment relies on reports from the people who know the child best—his or her caregivers. The caregivers then understand the purpose of the goals and the anticipated benefits.

Goals are directly related to routines and enable children to be more independent and successful in their current environments. Goals are not just isolated skills drawn from a test or curriculum—skills that might be irrelevant to the child's daily life.

Few if any modifications are made to existing routines. These goals do not require an adult to spend extended periods working one-on-one with a child.

At the Individualizing Inclusion in Child Care model demonstration sites, the routines-based interview is used to identify goals for the child's individualized family service plan (IFSP) or individualized education plan (IEP). Even if a child care program is not familiar with this type of assessment, families can use the information about routines-based assessment to find out what programs do in order to plan for an individual with special needs in the classroom, or advocate for such an assessment to be used in planning for their child.

Ask the child care professional/ Observe in a classroom

- Are children interacting with peers, materials, or adults the majority of the time?
- Is independence fostered among children?
- What do the teachers do to promote children's social relationships?
- How do teachers identify and address children's individual needs in classroom routines?
- Did a professional from the center (e.g., classroom teacher, director) ask about the family's overall concerns for their child?
- What is the classroom schedule for the children in the child's age group?
- Will the child's teacher participate in the development of the child's IFSP/IEP? How can services be coordinated to ensure that all the professionals working with the child are working together?

There are numerous challenges to regular and effective communication among professionals. Lack of communication can cause duplication or gaps in services and inconsistencies in interventions. An integrated approach to therapy provides frequent opportunities for professionals across disciplines to communicate and coordinate services.

Integrated therapy is the provision of specialized services (e.g., physical therapy, occupational therapy, speech/language pathology, and special education) in the classroom within the context of daily routines. When therapy is provided in the classroom:

- four times as much communication takes place between the specialists and classroom teachers than when therapy is provided in a therapy room or other location;
- teachers get on-the-spot technical assistance and models by specialists;
- specialists see what children are and are not able to do in their natural environments;
- children get help with needed skills when and where they need it; and
- children generalize skills addressed in in-class therapy more than skills addressed in pull-out therapy.

Many specialists can provide therapy services in the child care setting. Families can tell service providers that they want therapy to be provided in their child's natural environment (one of which is the child care program). Teachers and specialists should determine which time of the day would be most appropriate for the specialist to come (e.g., if the SLP is going to work with Katie on using a communication board to interact with peers, she would not want to come at a time when the class is outside, doing water play). When specialists are in the classroom, teachers should try to be available to observe or talk with the specialists.

Ask the child care professional

- Do the teachers have experience working with specialists?

continued on page 50

continued from page 49

- Are specialists invited into the classroom to observe, provide therapy and consult with the teachers?
- Who will be responsible for giving information to and obtainingit from all professionals working with the child?
- What kinds of resources are available for the teachers?

Ask the specialists:

- Will they provide services in a child care classroom? Do they have experience working in classrooms?
- Are they willing to consult with child care providers about the child's needs and interventions? How will the child's developmental skills be addressed and extended to ensure that the child is reaching his or her full potential?

We know that children learn best when they are given multiple opportunities to practice skills across the day. By focusing on the skills a child needs to use in daily routines, caregivers are able to embed intervention strategies throughout the day, giving children many meaningful and relevant chances to practice. Embedded intervention is simply inserting intervention strategies into activities in which the child is engaged.

Ask the child care professional/ Observe in a classroom

- What is an example of something you are working on with a particular child?
- How do you work on this skill (e.g., isolated from other people versus with other people present)?
- What are the most important things you teach children? Hint: getting along with others, independence, fostering interests; not ABCs, numbers, and colors.
- Would individualized needs be addressed in one-on-one sessions or during the child's regular play routines?

When children have difficulty learning, how is this handled? Hint: One-on-one versus integrated into routines.

- About what percentage of the routines do teachers use to address individual needs?

For children with disabilities to have high-quality inclusive child care experiences, individual needs must be addressed in an individualized manner. The Individualizing Inclusion in Child Care project model has identified three key components for ensuring such experiences. The secret of successful inclusion, therefore, is a combination of:

- assessment about what really matters—routines;
- therapy and special instruction in the classroom with teachers involved; and
- special help woven into regular classroom routines. ■

Stacy Scott, M.Ed. is the project coordinator for the Individualizing Inclusion in Child Care model demonstration project, The University of North Carolina at Chapel Hill.

R.A. McWilliam, Ph.D. was a senior scientist at the FPG Child Development Institute at the time of writing. He is now at Vanderbilt University Medical Center.

STATEN ISLAND'S PS 37: A SCHOOL OF OPTIONS—

AND AN EXAMPLE OF HOW INCLUSION CAN WORK.

By Maria Tortoreto

Evelyn Phair Finn wants nothing more than to see her students excel. She knows each by name, and walks around the halls giving each a hug as they smile and laugh with her. As principal of Public School 37, A School of Options, Staten Island, NY, she has the highest regard for the future success of her students with disabilities. Inclusion programs are a great tool for this success.

Inclusion affords students with disabilities the chance to be in regular classrooms and interact socially and intellectually with general education students.

"Inclusion is a wonderful program," according to Staten Island Inclusion Facilitator Laura Towey. "It benefits not only the special needs students, but the general education students as well. By exposing them to each other, they get to learn and live with each other."

With many new early intervention programs in Staten Island getting under way, children with mild disabilities are able to get the extra attention that they need in pre-k and kindergarten, and eventually are able to move into regular schools in inclusion programs.

Towey has been working with Finn and the School of Options for ten years, finding and persuading regular districts to be open to the idea of inclusion. So far, the success of all students has been phenomenal.

Candidates for the inclusion program are chosen through parent or teacher requests. They are put into age-appropriate classrooms and work is adapted or modified to fit the ability level of the students, allowing them to be involved with the rest of the class.

No fewer than two special-needs children are put in one class, along with a SETS (Special Education Teacher Supports) professional. This person works directly with the teacher and the parents, as well as with the students, to keep everyone on the same page.

Says Towey, "Kids want to be like other kids, which is the best motivator for learning. Our students do things in inclusion programs that they'd never be able to do otherwise."

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

1027

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #58 or visit www.eparent.com/adinfo

EDUCATION 2002

A TEST OF FAITH:

College Testing Services Will Stop Flagging Scores

By Julia Steele

In a move that will help students with disabilities, but may hurt the fairness of test administration, the College Board and ACT will no longer identify test scores obtained under special conditions. This will affect all College Board standardized tests, including the Scholastic Aptitude Test (SAT), the College-Level Examination Program (CLEP) and the Advanced Placement Program (AP), as well as the ACT college entrance exam.

"Special conditions" usually refers to extended time limits, but can also mean special computer set-ups, readers, scribes or other accommodations. The practice of identifying test scores obtained under such conditions is known as "flagging," and consists of including asterisks or the words "nonstandard administration" on score reports to alert college admissions offices and anyone else who may see the scores that accommodations were made.

The decision to discontinue flagging came after the case of Breimhorst v. Educational Testing Service (ETS), C-99-3387. The ETS is a nonprofit organization that develops and administers standardized tests. ETS tests include the Graduate Requirement Exam (GRE), Graduate Management Admissions Test (GMAT) and the Test of English as a Foreign Language (TOEFL), among others.

> Section 504 states that no "otherwise qualified individual with a disability" shall "be subjected to discrimination under any program or activity receiving federal financial assistance."

The case involved Mark Breimhorst, who in 1998 took the GMAT in preparation for applying to business school. Because he has no hands, Breimhorst was given permission to take the test on a computer with a trackball, as well as a 25-percent increase to the time limit. When his scores came back with the special conditions indicator included, Breimhorst called the ETS and requested that the notation be removed. They refused.

In July 1999, Disability Rights Advocates (DRA) of Oakland, CA filed a suit against the ETS on Breimhorst's behalf. They alleged that test score flagging is a violation of the Americans with Disabilities Act (ADA) as well as Section 504 of the Rehabilitation Act, since ETS receives federal funding. Section 504 states that no "otherwise qualified individual with a disability" shall "be subjected to discrimination under any program or activity receiving federal financial assistance." It was argued that flagging is a stigmatizing practice that constitutes discrimination. Organizational plaintiffs in the case included the International Dyslexia Association (IDA) and Californians for Disability Rights. The suit sought injunctive relief to end flagging, as well as compensatory, treble and punitive damages.

District Court Judge William Orrick, in the denial of an ETS motion to dismiss all charges, wrote, "If the testing provider complies fully with the requirement that its tests measure equally the abilities of disabled and nondisabled test takers, there would be no need for flagging."

Breimhorst and ETS reached a settlement in which ETS agreed to cease flagging on all ETS tests as of October 2001. While it is a separate entity from the College Board, the ETS develops and administers tests owned by the College Board, such as the SAT and AP. It was agreed that a panel would be convened to examine the practice of flagging on College Board tests. It is this panel which announced the recent decision that the College Board will no longer practice flagging on its tests as of October 1, 2003.

Following the College Board's decision, the ACT announced that it, too, would stop flagging as of fall 2003. While the SAT is the leading college entrance exam, the ACT is dominant in about 27 states, particularly in the Midwest. Most colleges will accept either test.

The decision to stop flagging is seen by disabilities activists as a considerable victory. But while most people

continued on page 54

Independence means different things to different people. For children with bladder or bowel control problems, it could just mean getting through the day dry. That's why something as simple as a change in clothing can, even in a small way, change a child's way of life.

GoodNites® absorbent underpants can help a child become more independent. With GoodNites, accidents won't become catastrophes. So your child will be able to do more. Plus, because they look like real underwear, kids don't mind wearing them. And since they're easy to pull on and off, they can make a child feel more self-reliant.

WHY CHILDREN WHO RELY ON GOODNITES ARE MORE INDEPENDENT.

Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS
45 lb & over

For Better Days

GoodNites are available in 3 sizes: 45–65 lbs., 65–85 lbs., and 85–125 lbs. That means finding the size that fits your child will no longer be a problem. Plus, they have tear-away sides and they're latex-free.

- *Day and nighttime protection*
- *Latex-free*
- *Tear-away sides for easy removal*
- *Three sizes, to fit kids from 45–125 lbs.*

Imagine your child gaining a little more independence just from a change in clothing. For information on how GoodNites can help, please visit us at www.goodnites.com/sn.

BEST COPY AVAILABLE

®Registered trademark of Kimberly-Clark Corporation. ©2002 KCC.

Circle #57 or visit www.eparent.com/adinfo

VISION
By VIEWPOINT MOBILITY

The **VISION** Advantage:
- Rear entry design doesn't limit you--park and go anywhere
- Not a bulky full-size van-- VISION can fit in a small garage
- Everybody can ride-- seats up to 7 passengers or 2 wheelchairs
- Conversions available on Chrysler and Ford minivans

Let VISION take you on the road to opportunities.

For a **Free Video** or a personal demonstration of the **VISION** call
Toll Free 1-877-368-6022

Circle #88 or visit www.eparent.com/adinfo

MANSEF
P.O. Box 6815
Baltimore, MD 21285
410-938-4413

MANSEF *Inspiring Dreams, Changing Lives*

For over 25 years, the Maryland Association of Nonpublic Special Education Facilities has been providing optimum educational opportunities for children and youth with the following disabilities:

- mental retardation
- hearing impairment or deafness
- speech or language impairment
- visual impairment or blindness
- emotional disturbance
- orthopedic impairment
- specific learning disabilities
- traumatic brain injury
- autism
- developmental delay

www.mansef.org

Circle #61 or visit www.eparent.com/adinfo

A TEST OF FAITH:

continued from page 52

involved agree that it's the right thing to do, many of them have concerns about how it will play out. Many feel that flagging served to help discourage those who don't really need special accommodations from abusing the system. Now, with nothing to suggest to colleges and others that extra time was taken or that other adjustments were made, many fear that there is no real motivation for students not to argue for exceptions if they possibly can.

There is also concern about how the disuse of flagging may widen the gap between students from affluent families and those from families without much money. Already, some families try to beat the system by pushing for a diagnosis for their child, hoping to buy them extra time on standardized tests. A recent study showed that students in private schools are four times more likely to receive accommodations during testing than students from public schools. With flagging gone, many fear that this disparity will become even more pronounced.

Both the College Board and the ACT plan to avoid abuse of the system by continuing the process of documentation reviews. Anyone who requests accommodations must have proper medical documentation to indicate the nature and functional limitations of their disability, as well as additional documentation stating exactly what accommodations are necessary. Often, test takers must receive accommodations when taking exams in school to qualify for accommodations on standardized tests.

Other common standardized tests not owned by ETS, ACT or the College Board still practice flagging. These include the Law School Admission Test (LSAT) and the Medical College Admission Test (MCAT). The DRA says they are receiving complaints about these exams as well. The end of flagging in general may not be too far off.

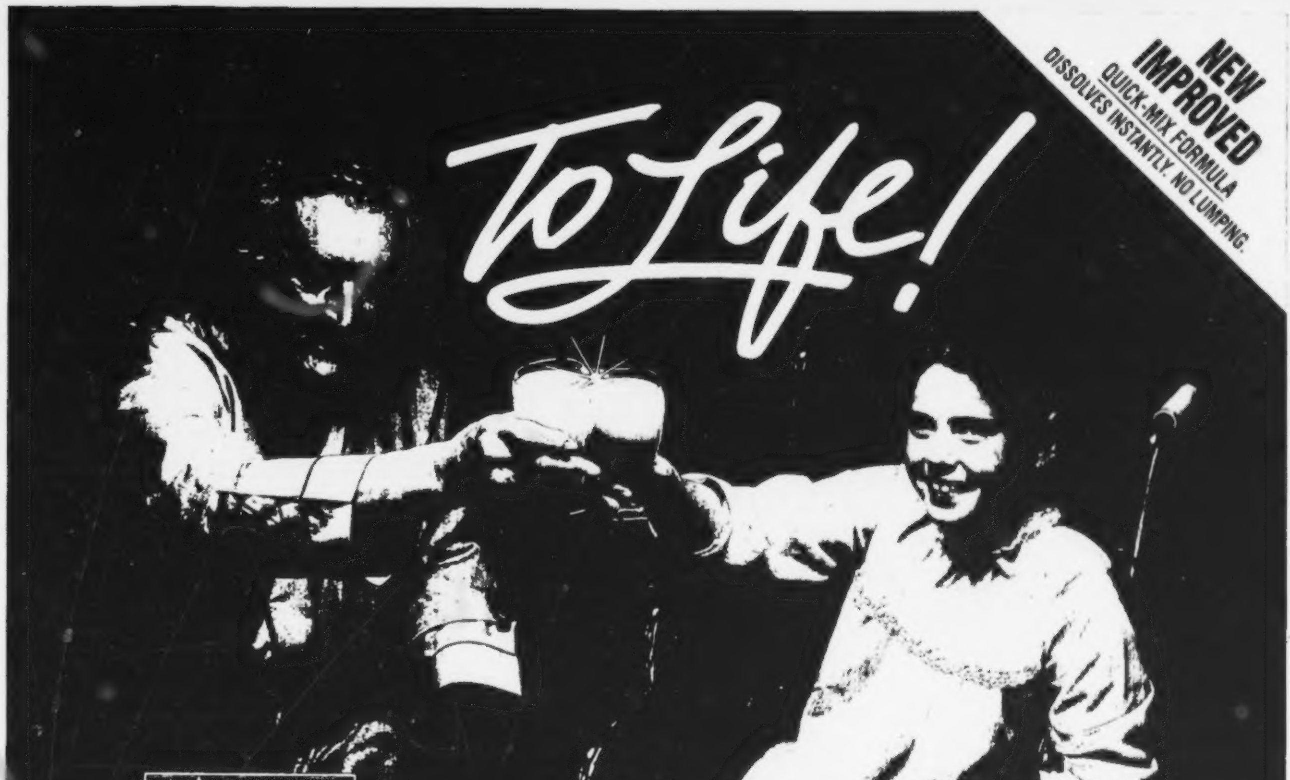
Meanwhile, testing services are left with the difficult task of determining how to make accommodations that will provide total fairness in administering tests to people with a variety of needs. It is relatively simple to provide someone who is blind with a test written in Braille. But exactly how much time will even the playing field for someone who is dyslexic, and what conditions are most appropriate for someone who has ADD or ADHD? These questions and more will become all the more important with the cessation of flagging. **EP**

For more information on the College Board, visit http://www.collegeboard.com.

For more information on the Educational Testing Service, visit http://www.ets.org.

For more information on the ACT, visit http://www.act.org.

1030


NEW IMPROVED
QUICK-MIX FORMULA
DISSOLVES INSTANTLY. NO LUMPING.
To Life!

DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

For product literature and advice, a free sample and information where **DIAFOODS THICK-IT** may be purchased, **call... (800) 333-0003.**

Free educational material, call... (800) 333-0003.

The booklet **"Dysphagia, A Review For Health Professionals"** discusses causes, evaluation and treatment of dysphagia.

The pamphlet **"Swallowing Problems"** helps patients and caregivers understand and adapt to dysphagia.

©1996 PRECISION FOODS, INC.
2150 N. 15TH AVENUE
MELROSE PARK, IL 60160
TELEPHONE (708) 216-0704
FAX (708) 216-0709

BEST COPY AVAILABLE

Circle #73 or visit www.eparent.com/adinfo

DD-SNAP

By J. Michael Hennike

Parents and families of children who have a developmental disability have all experienced the process of evaluations and assessments. The process has historically been conducted by a professional or team of professionals in the field of developmental disabilities ("DD professionals") using informal and formal assessment methodologies, including standardized assessment tools, structured interviews, etc. The assessment process has traditionally led to the acquisition of information designed to provide a diagnostic outcome or more often an assessment of the person's needs for services and support.

The assessment protocol that has typically been employed is a "professional-centered" one in which the person and the family are primarily respondents to the various tools and methods employed. Frequently, this process has as its focus the identification of deficits, limitations and dysfunctions of the individual being assessed. The recent advent of person-centered supports, self-determination and the empowerment of the individual, parents, and families has reduced the focus on deficits. Person-centered models have also created a more proactive, choice-driven system in terms of the supports a person requests and receives.

Despite the improvements in choice and the arrangements for acquiring support, the assessment of need for services and support remains primarily a "DD professional-based model." The process still entails the use of assessment tools for establishing eligibility for support and for determining a person's qualification for categories and levels of support. A professionally-conducted assessment of need for support does not, however, preclude an assessment of need by a person who has a disability, or by a parent or family member of a person with a developmental disability. In fact, this author would contend that a person/parent/family member assessment of need for support should be an integral part of a comprehensive needs assessment protocol.

The Developmental Disabilities Support Needs Assessment Profile (DD-SNAP) is a needs assessment instrument used by qualified DD professionals for determining acuity of level of need for persons with developmental disabilities. It is not deficit focused. It is focused on needs. This standardized assessment tool is used in a variety of states as a requisite part of support planning, eligibility and resource allocation.

The DD-SNAP provides, on a scale with five levels, need indexes in three important domains: daily living, health and behavior. From these three domains comes an overall level-of-need index, showing a range from low need (Level 1) to very high need (Level 5). This instrument has a structured, competency-based training requirement in order for DD professionals to be certified in its use. It is, nevertheless, a very straightforward, easy-to-use, self-scoring and easy-to-understand assessment tool.

The DD-SNAP will be used this year with 27,000 people in the North Carolina Developmental Disabilities service system as a first step in the development of an individual plan for support. The instrument also has an optional structure which can be used to aid in plan development. It is not a prescriptive tool in that it does not dictate a type of service or support, but instead it reveals the level of support required. The type of service selected to meet the need level becomes a matter of choice for the person, the family, and the support system.

The DD-SNAP protocol would be a very useful tool to be used in a parent-empowered assessment process. An assessment conducted by parents, guardians or close family members using the DD-SNAP would help structure and organize their knowledge of the individual's needs in important areas of life. The DD-SNAP assessment, when administered by parents or guardians, would facilitate the communication between support managers, brokers/providers and recipients of support. The use of this assessment tool by parents and families would also serve to empower them in their efforts to obtain necessary and desired supports.

The DD-SNAP training protocol and competency-based outcome model should be provided to parents of persons with a developmental disability who are interested in acquiring assessment skills. The training needed to meet the DD-SNAP competency requirements, if provided to parents, could equip them to meet the challenge of representing their best interests in arranging for support. In fact, around 150 parents and families in the state of Tennessee have already been trained to use the DD-SNAP as a self-assessment of need for support and services. These families did find a high level of congruence between their assessment and one completed by a trained DD professional. Where significant differences did exist between the DD-SNAP self-assessment by families and those conducted by professionals, the families were empowered to exercise the appeal prerogatives in a knowledgeable manner.

The DD-SNAP can also serve as an extremely useful tool for parents and families to periodically assess changes in the intensity of needs and the types of needs of their child or family member. Periodic assessment using the DD-SNAP to determine support needs can be an important monitoring device for families and can assist them in obtaining a review of the service array necessary to meet the recipient's needs.

In conclusion, it is important for parents and guardians to be empowered in the needs assessment process. This can be fostered by providing competency-based training that will equip them to conduct a formal assessment of need for their family member using the DD-SNAP. This assessment protocol will enable parents and families to effectively communicate needs for support with DD professionals. Whether the needs are daily living supports, health supports or behavioral supports, the parents/guardian will have a common frame of reference for measuring intensity of needs that is compatible with others responsible for providing supports and services. EP

Michael Hennike is the director of the Murdoch Center in Butner, NC. The Murdoch Center, in affiliation with the North Carolina Department of Health and Human Services, provides comprehensive residential care for developmentally disabled residents from sixteen counties in the North Central Region.

Autism Treatment Research

Seeking children with autism to participate in a FDA approved study in children under 5 years old of synthetic human secretin.

This double-blinded, placebo-controlled study, is designed to:
evaluate improvement in social and communication symptoms of autism
evaluate the safety of 6 doses of secretin over 15 weeks.

Sponsored by Repligen Corporation.

For more information visit:
www.autismtrial.com or
Call 1-800-622-2259, press "5"

☆ - Clinical Trial Sites

Circle #76 or visit www.eparent.com/adinfo

EDUCATION 2002

PARENT PERSPECTIVE

Homeschooling

In June 2002, EP asked our readers to tell us why they have chosen to homeschool their children with disabilities. Here are some of the answers we received.

THERESE AND MIKE COOPER

We will begin homeschooling our three-and-a-half-year-old daughter, who has Down syndrome, this fall. We have made this choice, for now, because we believe that knowing her best, we can impact her the most. She will not have to make the typical out-of-home school adjustments and will be able to enjoy the pleasure of learning. At home, I can be flexible to teach her when I know she is most receptive, and can more easily work with her medical needs. My husband can also be a part of her education journey. She will have the advantage of having teachers who know her for who she truly is, and not have to function under the treatment of a label. Her unseen potential is recognized and regarded as a real, life-giving component of her program to us. Just as each of her siblings, she will contribute her God-given gifts to her school environment and to the world. We are most interested in contacting other families who are homeschooling children whose abilities are challenged.

LEVERNIA@AOL.COM

I am the parent of a five-year-old little boy with CP. I decided to put him in homeschooling this fall. We live in a very rural area and the school system doesn't know where to begin or to end. The nearest place for my son to learn different opportunities is an hour away. We are still working on a program for my son. Right now our main subject is learning some type of communication. He is currently working on the Dynavox. This is been somewhat of a struggle for us. He has a hard time adjusting to new things and he also has such a strong determination, but we are not quite sure how to make him understand how to work with his body. As far as his teachers, who come out to help, they find it hard to learn the Dynavox or they just don't want to. My main reason for putting my son in homeschooling is because of the lack of technology the school has to offer, the ignorance of people caring for children like my son and the poor atmosphere they put him in.

Thank you for listening and caring.

DARLENE JENSON

Our son is now eight years old, and we have been homeschooling for two years. He has CP, mental retardation and a seizure disorder. We live in a small town in southern Vermont and our school options are limited. We received services from the Family, Infant, Toddler program when he was young, and then went on to the school district's Early Essential Education classroom (EEE). We requested an extra year in the EEE classroom, despite the fact that he was then six-years-old in the traditionally three- to five-year-old classroom. We strongly felt that he could (and did) benefit from remaining in the preschool-based curriculum rather than moving on to kindergarten. When the time came to make the decision to move him on to kindergarten, we again did not feel that he was ready for an academic-focused curriculum, as he was only just beginning to understand and respond to a more play-based, preschool program.

All this raised the question of developmentally appropriate curricula. For typical children, this means a curriculum based on their developmental age in relation to their learning styles, and the development of their social and cognitive skills. There are many educational theories for designing a curriculum based on a child's developmental needs. In our school district the educational norm for special education is to integrate the special ed students by keeping them with their chronological peers. This presented a problem for us right from the start, as our son's developmental age is closer to a preschooler and may remain that way for who knows how long. We imagined that our child might do okay in kindergarten, but what about when he's in fourth grade, sixth

continued on page 60

I want to make sure he's cared for all his life.

I'm Sarah, 43.

My son Jeremy has overcome many obstacles.

Financial insecurity shouldn't be one of them.

MetDESK

My husband Bob and I want to make sure Jeremy is provided for when we're not around any more. So we talked to MetLife. Their MetDESK (Division of Estate Planning for Special Kids) specialists helped us with the many financial and legal issues in providing quality lifetime care for Jeremy. Since many of the MetDESK specialists are parents of children with special needs, they're knowledgeable and understand families like mine.

For more information on MetDESK call 1-877-MetDESK (1-877-638-3375). Ask for our brochure *Planning for Your Child with Special Needs* or visit our web site at www.metlife.com/desk.

GET MET. IT PAYS.

MetLife
Financial Services

PEANUTS© United Feature Syndicate, Inc. Metropolitan Life Insurance Company L00124ROY(exp1205)MLIC-LD

Circle #65 or visit www.eparent.com/adinfo

1035

continued from page 58

grade and beyond? Sure, there is a special education "classroom," but mostly the children work with their one-to-one aides on their IEP goals. Our child is very social, very musical and very expressive even though he is non-speaking. The idea of him spending most of the day with one adult did not appeal to us. Our thoughts turned to home schooling.

What a huge undertaking, we thought! What about socialization? Would it be enough for him? Would we be too isolated? Many questions came to us, but then we started to get excited about creating a school situation for him that was really about him and his developmental needs, not about trying to fit him into an existing system.

We called a local home child care provider and asked her if she would be willing to have our son in her program. She was very excited about this idea, and after meeting many times to explore the details we decided to take the leap into this new world of home schooling. We would be our son's aides as he attended her home child care program three mornings per week. There would be a small number of children; she would be in control of designing the curriculum and we would be right there to work along with her and our son. This was the answer for us: a way we could create a program for our son that met his developmental needs and allow us to remain in compliance with the school district's laws.

We registered with the Dept. of Education Home Study office and received lots of help putting our son's IEP goals into the correct educational categories, like science, social studies, government and literature. It was pretty overwhelming at first, but got much easier as the year progressed. Our son's whole curriculum is based on his own personal needs in relation to the physical, speech, occupational and social skills that he needs to work on. These curriculum goals came from his IEP, his private therapist's goals, his child care provider's goals and our family's goals for him based on what we all know he really likes and what he wants and needs to accomplish next.

Our first year went well. There were lots of details to work out and we all got a sense of what it really meant to "integrate" a special needs child with typical children. It is a difficult task and takes lots of patience, trust and role modeling on the part of the adults. Our son had a good year; he was exposed to many new situations, he learned lots of new social skills and he loved the play-based curriculum. We also met lots of other home schooling families through another group we participated in one day per week.

Our second year we increased his time and hired an aide to

Positive lifestyles
for people with developmental disabilities.

Residential, vocational and day programs are provided in a rural village setting. Residents enjoy community living, and a lifestyle designed to appreciate their individual characteristics. Respite care is also available.

Martha Lloyd

190 West Main • Troy, PA 16947 • (570) 297-2185, Ext. 268
www.marthalloyd.org • E-mail: information@marthalloyd.org

Circle #62 or visit www.eparent.com/adinfo

Discover
New England Village, Inc.
"A community rich with opportunity, sharing and growth"

Established as a non-profit corporation in 1972, New England Village is a warm, caring, stable and secure environment where young adults with mental retardation can lead a high quality lifestyle with opportunities for growth and friendship.

Our campus, set on 80 beautifully wooded acres just 25 miles south of Boston, offers attractive contemporary style homes and townhouse apartments. Learn about our full range of residential options, extensive vocational and educational programs, and wide spectrum of recreation and social opportunities. We invite you to meet our dedicated and caring staff and to speak with other families about our Village.

Call (781) 293-5461, x110 or write Judy Andracchio, Admissions Coordinator, to arrange your personal visit or request our brochure. We invite private and state-sponsored referrals.

New England Village, Inc.
664E School Street • Pembroke, MA 02359
781-293-5461 • www.newenglandvillage.org
info@newenglandvillage.org

visit www.eparent.com/adinfo

attend the home child care program with him so he could have a more independent experience. This worked very well and increased his opportunity for child-to-child interactions and involvement. Each year we expand the curriculum to fit the goals that he is actually working on. Sometimes that means that a goal we chose did not get fulfilled, but another goal took on more emphasis because he was developmentally ready to move in that new direction. Because we (including our son) are in charge of his learning and setting the goals we are free to be flexible and current with what he needs and wants to be working on. This is developmentally appropriate curriculum working at its best.

All in all, it has been a great experience for our family. We still have lots of questions and wonder if we are doing "enough," but the smile on his face when his aide rings the door bell, the way the children greet him with "his" sounds at the birthday party, and the way his peers take hold of his hand to give him hand-over-hand assistance to play with a toy is enough for us. Oh, and what about the quality of life issue? Well, I think for our son, making friends and making music, having new experiences and teaching others to embrace the simple pleasures in life is what having a good quality of life is all about. **EP**

National Association of Private Special Education Centers

NAPSEC is a nonprofit association whose mission is to ensure access for individuals to private special education as a vital component of the continuum of appropriate placements and services in American education.

Free Referral Service
NAPSEC provides information on potential placement options to parents and professionals who need an appropriate private special education and/or therapeutic setting.

National Representation
NAPSEC advocates for the rights of individuals with disabilities and their families.

Nationwide Membership
NAPSEC represents private special education facilities throughout the US by providing a wide array of membership services.

Private early intervention services, schools, residential therapeutic centers, and adult living programs serving individuals with disabilities and their families since 1971

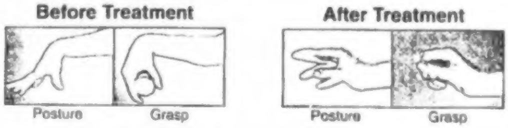
NAPSEC
1522 K Street, NW, Suite 1032
Washington, DC 20005
Phone: 202-408-3338
Fax: 202-408-3340
E-mail: napsec@aol.com
Web Site: www.napsec.com

NAPSEC

Circle #67 or visit www.eparent.com/adinfo

FIRSTFlex™
improving reach, grasp and pinch together.

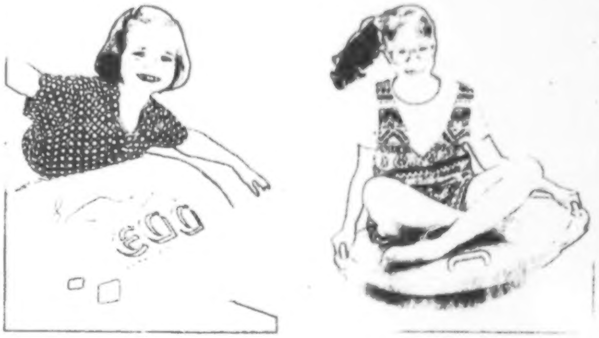
FIRSTFlex™, for children with spastic hemiplegia, combines patented bracing with electrical stimulation.

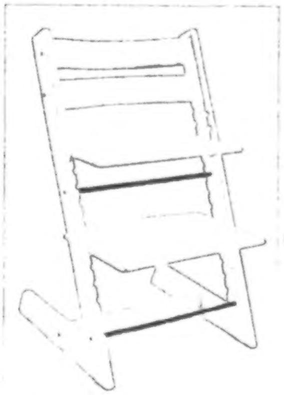


www.ultraflexsystems.com

Call 1-800-220-6670 for free video and research studies.

Circle #85 or visit www.eparent.com/adinfo





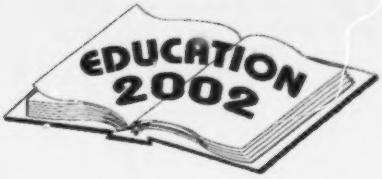
We Like Making Kids Happy ...

Send For Free Catalog

equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094

E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #42 or visit www.eparent.com/adinfo



401 KID

by Julia Steele

New tax laws are providing families with better ways to save for college. With tuition costs increasing at more than twice the rate of inflation, more and more parents are wondering how they will be able to afford higher education for their children. But thanks to recent changes in IRS code, new options are available.

Tax legislation called Section 529, passed about five years ago, is to higher education what a 401k plan is to retirement. Even though it has been around for a while, only 25 percent of parents are aware that it exists; 75 percent are missing out. This law allows for investments in "529 Qualified Tuition Plans" (QTPs) to grow 100-percent federally tax-free, and often state tax-free, provided that the funds are used for Qualified Higher Education Expenses.

While they do vary a bit from state to state, most 529 plans offer minimum investments as low as $25 and have generous contribution limits—over $250,000 in some cases. There can be other benefits as well, such as employer matching contributions. Since they are relatively new, 529 plan laws are still in flux and have a tendency to change rapidly, so be sure to find out what the rules are in your particular area.

401Kid®
Education Savings Plan

Certain restrictions prevent some upper-income families from participating, but anyone making less than $220,000 a year may open a Coverdell ESA, and may contribute up to $2000 a year. Typically, the account must be withdrawn by the time a child is 30 years old, but an exception to this rule is made for children with disabilities.

Another way to save on educational expenses is with Coverdell Education Savings Accounts (ESAs), formerly known as Education IRAs. Coverdell ESAs have been made tax deductible for education expenses in the K-12 years, including books, room and board, tuition and transportation. Unlike 529 plans, which are mostly handled by private investment companies, Coverdell ESAs can be opened through almost any bank.

Certain restrictions prevent some upper-income families from participating, but anyone making less than $220,000 a year may open a Coverdell ESA, and may contribute up to $2000 a year. Typically, the account must be withdrawn by the time a child is 30 years old, but an exception to this rule is made for children with disabilities.

In addition to the absence of a time limit on the funds, there are other for children with disabilities. For instance, certain tax credits may be taken for child and dependent care expenses. For parents with a dependent child going to college, the costs incurred are entirely tax deductible. This is not the case for non-disabled children. One thing to note, however, is that both 529 plans and Coverdell ESAs will affect a family's Expected Family Contribution when applying for financial aide.

There is a lot of information out there about these options, and sometimes it can all get a little bit confusing. A web site called 401kid (www.401kid.com) provides information about 529 plans and Coverdell ESAs and helps to break down the information. It also provides ratings based on relevant criteria, such as contribution ranges, plan expenses and tax benefits. While the site requires membership in order to gain access to most of its material, it does offer a basic membership for free. The site contains information for everyone from parents and students to educators, employers and fund managers. 401kid also offers various financial calculators and software packages, as well as consulting on a number of topics.

The key to making education more affordable is to start saving early, while children are still young. But through these options, parents now have better ways to make higher learning more financially accessible to their children. EP

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C. & Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #60 or visit www.eparent.com/adinfo

EDUCATION 2002

THE PARAEDUCATOR paradox

by Patricia H. Mueller, EdD

Somewhere along the line something went wrong. Special education has become a system that depends heavily on relatively untrained, underpaid, and devalued staff members to provide instruction to our most challenging students. That is what I call the "paraeducator paradox."

The following is a brief description of some of the larger issues and growing concerns that surround the employment, training, retention and support of paraeducators, and a list of steps that parents can take to help improve the situation. The ideas presented come from research; many are from the numerous paraeducators with whom I've worked over the past ten years. My hat goes off to those dedicated professionals!

ISSUES AND CONCERNS

Inadequate orientation and professional development

Paraeducators aren't "aides" anymore, running the ditto machine and performing clerical tasks. They spend most of their time providing instruction, and many report that they independently plan instruction for students. However, most paraeducators also report that they receive little or no training to perform these roles. Most training occurs on the job or from another paraeducator. If they do receive orientation training, the focus is typically on confidentiality, while many other important topics—orientation to the classroom and students, reporting suspected abuse or neglect, home/school communication—are not discussed.

If paraeducators are paid to attend the district in-service workshops, they often report that the topics are irrelevant. They also report inconsistencies in payment to attend either in-district or out-of-district in-service, thus decreasing their ability to access training opportunities.

Role Confusion from absence of a clear job description

Paraeducators frequently laugh when asked if they have job descriptions; many have none. If they do, most are out-of-date and no longer reflect the current role of the paraeducator. Many written descriptions add the phrase, "and all other duties as assigned by the supervisor (teacher, principal)." Paraeducators have often reported that they have been assigned tasks for which they felt they were not qualified, but obligated to perform. The effect of these practices is role confusion about who does what, when and with whom.

Poor supervision and lack of ongoing support

Many paraeducators indicate having little contact with supervising special and general educators. They are rarely observed and provided with corrective feedback. What support they do receive is from other paraeducators. As a result, they often feel isolated and alone.

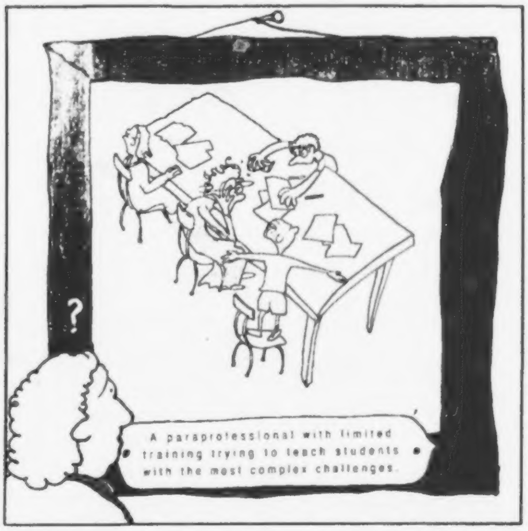
Inadequate performance evaluation

I think this quote from a Vermont paraeducator sums it up: "In the nine years I worked in this district, I have received two evaluations!" Paraeducators often report that they are evaluated infrequently and that, on those rare occasions, the evaluations are often conducted by administrators who are unfamiliar with the paraeducators' work, thus making the reviews irrelevant.

Lack of respect as an educational community member

Paraeducators continue to feel that they are the lowest on the totem pole. These feelings are certainly substantiated by poor salaries and benefits, a combination which causes many to leave the profession. Paraeducators across the country report that they do not feel they are respected or valued for their contributions, as so eloquently expressed by a Vermont paraeducator:

"The rewards to be had in doing this are from the kids. In the school where I work, paras are still thought of as housewives with part time jobs… We never know what is going on, but are expected to implement decisions that we are never a part of. As far as the pay goes, there is no differential for education or job performance. If you are one of the capable paras, you are asked to do more and more classroom teaching without any additional pay. If you love the kids and are


?
A paraprofessional with limited training trying to teach students with the most complex challenges.

© 2000 MICHAEL F. GIANGRECO. ILLUSTRATION BY KEVIN RUELLE
PEYTRAL PUBLICATIONS, INC 952-949-8707

WHAT'S WRONG WITH THIS PICTURE?

hooked on the learning process, the administration gets an extra teacher in the bargain. Recognition is pretty much lacking. If it were not for the parents and their children, paras would go pretty much unnoticed."

Overuse of paraeducators (the Band-Aid approach)

Assignment of paraeducators as the one and only method to support students in general education programs has skyrocketed (check your local school budget increases in the area of personnel). Paraeducators certainly do provide the support some students need, but they can also hinder a student's growth. For example, when a paraeducator becomes "Velcroed" to a student, the student's social interactions with peers can be significantly affected. Similarly, when a paraeducator becomes the student's primary teacher, the general educator abdicates responsibility for the student, further isolating the student. In such instances, the paraeducator may lack the necessary qualifications and training to effectively implement instructional and behavioral programs. As a result the student may not develop peer relationships or receive quality instruction. These situations illustrate what I refer to as "irresponsible" inclusion.

PROMISING PRACTICES

By now you have probably identified practices that may be in use in your child's district. Here are some proposed changes that can ultimately affect the quality of your child's education.

Cartoon appearing on this page reprinted with permission from
"Teaching Old Logs New Tricks: More Absurdities and Realities of Education"
by Michael F. Giangreco
©2000, Peytral Publications, Minnetonka, MN.

When possible, participate in the hiring process

Speak with your district administrator and ask to be a member of the hiring team. You may know the best "fit" (personality type) for your child. As a former district administrator, I know this participation may not always be possible, but your input can assist in the hiring, orientation training and ongoing relationship you will have with the paraeducator providing support to your child.

Develop comprehensive job descriptions

With input from paraeducators and other key staff, recommend to district administrators that they develop job descriptions that include qualifications needed for the position. These should include orientation and training requirements for the position, duties and responsibilities of the position and guidelines for supervision, ongoing support and evaluation. Model job descriptions do exist in various districts throughout the country.

Relevant orientation and professional development

Encourage your district to provide an orientation that includes a review of the district's/school's policies and procedures and orients the paraeducator to your child, the classroom and other staff that support your child. You may want to participate in this orientation effort, since you have valuable information about your child's learning style.

Paraeducators should help to build relevant professional-development programs that meet their unique needs. Some districts have created successful mentoring programs in which trained, veteran paraeducators mentor the "new kids on the block." Others have flexible in-house mechanisms for paraeducators to earn credit for the on-the-job training they receive. Work with your State Department of Education and institutions of higher education to develop appropriate training for paraeducators. Funding these initiatives is not as difficult as it may seem; many districts can access their professional-development funds or state/federal grant funds.

Adequate supervision and ongoing support

Special and general educators who supervise paraeducators need their own professional development program that describes how to best utilize these fellow teachers. Most have never received this information through their pre-service or in-service training programs. An excellent resource book, "Supervising Paraeducators in School Settings: A Team Approach" (A.L. Pickett and K. Gerlach, Eds, Austin, TX, 1997) can help your district to develop a strong staff training program. The National Research Center for Paraprofessionals in Education and Related Services provides training and technical assistance, disseminates information about promis-

continued on page 66

Adaptivemall.com™

Shop On-line!

Tim's daughter Carrie... a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.

Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #26 or visit www.eparent.com/adinfo

Camphill Special School

Children's Village

A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- Pennsylvania Approved Private School
- Waldorf Curriculum (Member of AWSNA)
- Both Day & Residential Programs Available

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236

www.BeaverRun.org

Circle #29 or visit www.eparent.com/adinfo

PARADOX

continued from page 65

ing practices in the field, conducts research and develops policy related to paraeducator issues and concerns.

Develop an appropriate evaluation system

Suggest linking the job description to the evaluation system, including professional goal setting, so paraeducators can determine how they want to grow during the year. Recommend that those educators who know the work of the paraeducator complete the evaluation, rather than an administrator or supervisor who lacks specific knowledge about the paraeducator's work.

Value the paraeducator as a part of the team

Acknowledging paraeducators for what they do can range from small things such as using the title "paraeducator" to increasing salaries and improving benefits. Paraeducators appreciate it when their input is recognized and valued, such as through participation in IEP meetings. Encourage teachers to value paraeducators as true team members. Help to educate community and school board members about the importance of these staff members. Suggest creating a committee made up of staff and community members to brainstorm cost-effective ways to celebrate paraeducator accomplishments.

Develop a process for determining when and if paraeducator support is necessary

One of my colleagues has developed a three-step team process to determine whether a student requires paraeducator support. The process identifies: 1) the specific student needs, such as safety; 2) what the student can and cannot do and the extent to which s/he needs assistance during the course of the day; and 3) where, when and how the paraeducator will provide support or encourage independence. Implementation of a process such as this ensures that students receive the level of support they need. It also encourages teams to actively discuss how peers will interact with the student, and how gradual independence will occur to the greatest extent possible. As parents, it's important to understand that assigning a paraeducator to support your child 100 percent of the day may not be of benefit.

Review staffing assignments

Districts that assign paraeducators to classrooms and/or to teachers, not to individual students, help to avoid the "Velcro effect." Assigning paraeducators to work with a variety of students and developing job-share positions for students with intensive needs are strategies that deal with student dependency issues and help reduce paraeducator burnout.

I hope this article has given you the opportunity to think about some of the challenges facing you and your school system in the hiring, employment, deployment, training, support and evaluation of the paraeducators who are probably providing significant levels of direct instruction to your child. The "promising practices" described are a reality in schools across the country. If you work collaboratively with your district to develop comprehensive processes and strategies that will support your children, they will be as successful as you know they can be. Readers can contact me for models, resources and/or references. There's a lot out there, so the wheel doesn't need to be reinvented. EP

For nine years, Dr. Pat Mueller coordinated the University of Vermont's Certificate of Study Program for Paraeducators that prepared paraeducators to work in inclusive schools and community settings. Dr. Mueller is the President of Evergreen Educational Consulting, a consulting firm in Vermont that provides professional development and technical assistance to state Departments of Education, local school districts and other agencies interested in developing qualified and dedicated educational support teams.

The author would like to thank Fran Campbell and Joyce Brabazon of Parent to Parent of Vermont for their thoughtful editorial reviews and comments.

RESOURCES

Pickett, A.L. (1999). Strengthening and supporting teacher/ provider-paraeducator teams: Guidelines for paraeducator roles, supervision, and preparation. National Resource Center for Paraprofessionals in Education and Related Services, Center for Advanced Study in Education, Graduate Center, City University of New York.

Pickett, A.L. & Gerlach, K., Eds (1997). Supervising paraeducators in school settings: A team approach. Austin, TX: Pro Ed. Pub.

National Resource Center for Paraprofessionals in Education & Related Human Services. Utah State University, 6526 Old Main Hill, Logan, UT 84322-6526. Phone: (435) 797-PARA. FAX: (801)273-7026. E-mail: mlikins@uswset.net.

Patricia H. Mueller, Ed.D. Evergreen Educational Consulting, 10 Chesnut Lane, Essex Junction, VT 05452. Phone: (802) 951-8210. Fax: (802) 951-8222. E-mail: Evrgreduc1@aol.com.

Anchors in different locations when needed

SUREHANDS®

Gary L., accountant, Warwick, NY - Becker's MD

At last, a Lift & Care℠ system as versatile as a pair of hands...and portable, too.

It's a motorized transfer device,
a positioning tool *for posture seating*,
a bathing support,
a hygiene helper *for toileting or diapering*,
a floor space-saver,
a standing support *for some*,
a dressing assistant,
and a back-saver *for carers*.

SUREHANDS LIFT & CARE SYSTEMS
Portable and permanent solutions for homes and workplaces.
1-800-724-5305
e-mail info@surehands.com • website www.surehands.com

Circle #82 or visit www.eparent.com/adinfo

Give your child the best care available!

Academic, Social, and Living Skills Instruction

Residential Programming

Employment Skills Instruction

Full Range of Therapeutic, Psychological, and Social Services

Respite Care

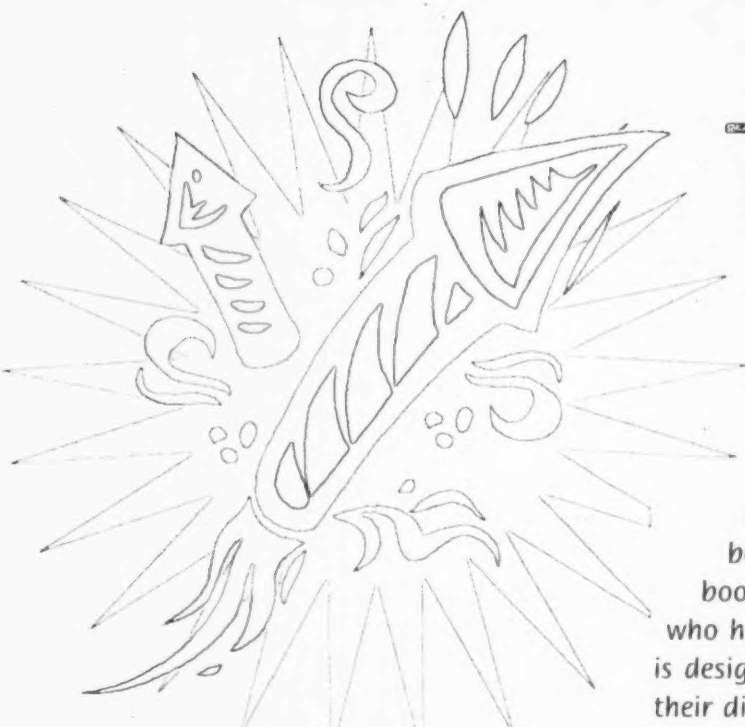
Safe Rural Environment

Located on Maryland's Beautiful Eastern Shore, Benedictine Programs and Services has provided the best programming available for children and adults with developmental disabilities since 1959.

BENEDICTINE
PROGRAMS & SERVICES

www.benschool.com
410.634.2112

Circle #25 or visit www.eparent.com/adinfo



Toolbox of Hope

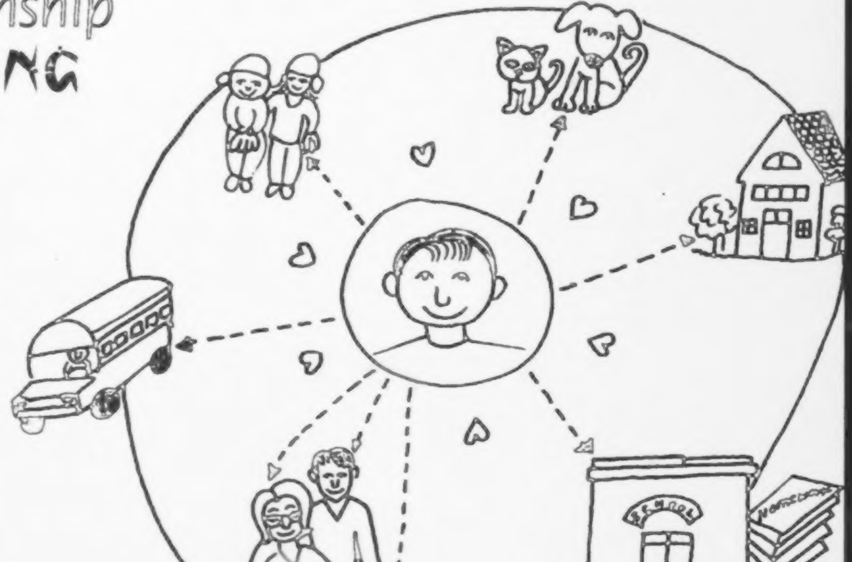
All children suffering from chronic, degenerative or terminal illnesses can benefit from using Toolbox of Hope, a workbook for kids. Created by Deva Joy Gouss, who has rheumatoid arthritis, this unique book is designed to help children come to terms with their diseases. Parents and teachers can use the activity outlines to help them and their children understand the feelings of confusion kids deal with every day.

For more information, visit the website at http://www.toolboxofhope.com.

THINK ABOUT IT!

You have a relationship with EVERYTHING in your life!

This includes your family members, friends, pets, all other animals, school subjects, activities, sports, your home, your school, your teacher, your parents' car or the bus you ride. The list can go on and on. Call upon the friend in you! Get personal with everything in your life!



1044

There are four rules of thumb when it comes to the importance of feelings! Here they are:

1. It is important to know how you feel! Name your feelings!

2. It is important to give yourself permission to feel whatever you feel!

3. It is important to express your feelings in safe ways!

4. It is important to think good thoughts and do good things for yourself - you deserve it!

SADNESS:

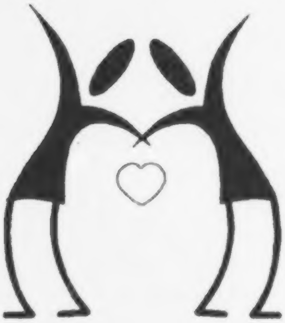
When you feel sad, it's very important to feel comforted and loved. Love heals!

Here are some special tools for you to use when you feel sad:

Curl up with your favorite blanket, stuffed animal, doll, or your pet. Find anything that you feel especially close to and have a good snuggle!

JOY:

Joy and happiness are just as important to feel and express as the more difficult feelings. Let yourself dance and move with the good feelings in your body.



Share your joy and love with other people and animals. Give and receive hugs!

Roll in the grass! Smell the flowers! Look up into the sky, throw your arms out and breathe, sing, dance, twirl! Be joyous!

Do some of your favorite things!

Make gifts for the people you love!

WOW!

All this joy, gratitude and self-appreciation!

We are already into the fourth rule of thumb for expressing feelings:

Think good thoughts and do good things for yourself!

REVIEW OF THE TOOLS:

- Share your story
- Gather information
- Create a relationship with your illness
- Name, give permission to and express your feelings
- Think good thoughts and do good things for yourself
- Learn to meditate, be grateful and find peace
- Think about "The Bigger Picture"

TOOLBOXES ARE HELPFUL IF YOU USE THEM.

Everyday, write a page about how you feel or draw a picture of your feelings. When you are feeling alone, scared, sad, angry, bored or glad, open up your toolbox!

Remember, your toolbox can be a great friend!

Applaud yourself for doing such a GOOD JOB with your toolbox!

Celebrate— You are on your way!

BEST COPY AVAILABLE

By Laura Apel

BRAVEKIDS.ORG

privacy policy
CLUB BRAVEKIDS
club home
about us
win
subscribe
team bravekids
games

Bravekids.org is one of the three programs offered by the non-profit organization Brave Kids, founded by Kristen Fitzgerald, who suffered the loss of two children to catastrophic illness. Through bravekids.org she is successfully helping others to prevent similar situations.

The website provides children who have chronic, life-threatening illnesses or disabilities with knowledge and information that can aid them in their daily experiences.

The site includes:

- Message boards that offer children and parents from around the world a place to connect with one another, lend support and share common situations;
- A Directory of Healthcare Resources which enables parents and caretakers to easily locate the nearest healthcare resources needed for ill children;
- The most recent and accurate medical information for children and family members presented in an interactive format geared towards providing the information in a fun and relateable fashion; and
- Interactive games and contests for children with special needs that offer winners wonderful prizes and the opportunity to be featured on the website and in the Brave Kids newsletter.

The web resource for kids with chronic or life-threatening illnesses

BraveKids.org

Club Bravekids is also included on the site. It offers children with special needs the chance to join an online club where they can vote on weekly polls, participate in games with one another, join various contests, utilize message boards, read news about other Brave Kids and research medical information that is created just for kids and teens.

Bravekids.org is easy to navigate and extremely dedicated to catering to the needs of children with disabilities and their parents. The opening page presents the Research Directory Search that offers information on everything from camps and clothing to respite care and transportation, all listed alphabetically. With the simple click of a mouse, those interested are immediately provided with a wealth of data on a particular topic. The search can also be specialized if a specific disease or condition is selected and the postal zip code entered.

Bravekids.org

Overall, bravekids.org is a web site that was designed for children with special needs and is thorough in its dedication to that cause. Every element of the site supports the mission of Brave Kids: to help children with chronic, life-threatening illnesses or disabilities. EP

Do you or someone you know have ADHD?

If you or someone you know experiences one or more of the following challenges often displayed by those who have ADHD, you may be interested in a breakthrough technology program called Interactive Metronome® (IM).

_ **Poor Coordination**

_ **Difficulty focusing/concentrating**

_ **Difficulty with language processing**

_ **Difficulty with reading fluency**

_ **Aggressive behavior**

Findings from a double blind, placebo controlled study on subjects diagnosed with ADHD showed those who completed the IM program saw improvements in attention, coordination, control of aggression, reading and language processing. This study was peer reviewed and published in the *American Journal of Occupational Therapy*.

Interactive Metronome is a non-invasive software program proven to produce significant gains in all of the above areas in just 3-5 weeks. This innovative technology program is available through your local health-care provider. To find an IM provider in your area, log onto www.interactivemetronome.com.

interactive metronome

Circle #92 or visit www.eparent.com/adinfo

They Have A Lot to Say...

and you can be the one to help them say it.

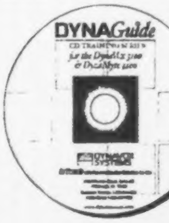
Since 1983, DynaVox Systems has been committed to helping individuals with speech, language and learning disabilities to lead fuller, more independent lives.

Our products are a part of a broad group of communication methods called *augmentative and alternative communication*, or AAC. DynaVox AAC devices help thousands of young people with speech disabilities due to cerebral palsy, autism, mental retardation and Down's syndrome to express themselves.

As the AAC industry leader, our success is based on a strong partnership with our customers. Our foremost objective is to ensure that our customers receive the best solutions to meet their immediate and long-term communication needs. This is enhanced by a comprehensive network of support services including:

- ***Funding Assistance***
- ***Product Training and Support***
- ***Expert Field Support***
- ***Telephone Customer Support***

All DynaVox associates are committed to the development of innovative services. Together we can achieve our goal as we continue to improve the lives of individuals with speech disabilities by bringing them the power of communication.

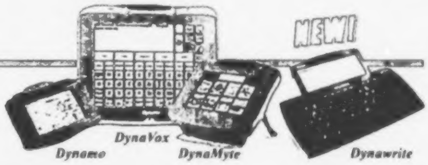


FREE!

DynaGuide Training CD included with the purchase of a DynaVox 3100, DynaMyte 3100 or Dynawrite.

KNOWLEDGE BASE
24/7
On-line Tech Support

Visit our 24/7
On-line tech support
at www.dynavoxsys.com!



DYNAVOX
a division of
SUNRISE MEDICAL
inTouch with Communication Solutions for Life.

For more information please contact our inside sales department at:
1-888-697-7332
www.dynavoxsys.com

Circle #40 or visit www.eparent.com/adinfo

0 1047

Special Report | Part IV: Family Wellness, Quality of Life and The Long View

by Susan Carucio Colacello

Long before our children are born, we envision who they will be, what great things they will do and how they will take the best of us and become even better. We risk facing our own mortality to peek into a future beyond our time, imagining their families, accomplishments, and contributions. They are the legacy we leave behind.

When our children do come along, we are well practiced at seeing the long view through our imagination. The challenge for all parents is to reconcile this imagined vision with the personalities, strengths and challenges of our real children. This can be exceptionally difficult when those children have disabilities and require unique supports and accommodations in order to access opportunities to learn, grow, work and live fulfilling lives.

> **"Vision...The ability to see beyond our present reality, to create, to invent what does not yet exist, to become what we not yet are. It gives us the capacity to live out of our imagination instead of our memory."**
>
> ***—Steven Covey, First Things First***

The first three articles in this series discussed parents' experiences and emotions as they move through the early years of raising, educating and securing medical care for their children with disabilities. Here we will look at the necessity of establishing a vision, or long view, that balances the parents' concern for safety with the adult child's need for independence, socialization and right to a productive and self-fulfilling life. Families who have found their children successful living and working placements agree that, although the process may be painful at times, it is immeasurably rewarding.

"The Vision Thing"

Valuable resources for parents ready to develop a vision and plan for the future can be found at kidstogether.org, a Pennsylvania-based advocacy web site developed by Colleen F. Tomko and her colleagues. They have put together a wealth of material to take parents through the process step by step. Ms Tomko suggests, "One way to start…is to begin thinking about where you and

continued on page 74

INFORMING EMPOWERING

AND KEEPING PARENTS INVOLVED

THIS SERIES IS MADE POSSIBLE BY AN UNRESTRICTED EDUCATIONAL GRANT FROM THE INTERNATIONAL FAMILY INSTITUTE AT THE CENTER FOR DISCOVERY IN HARRIS, NEW YORK. WWW.DISCOVERYIFI.ORG - WWW.THECENTERFORDISCOVERY.ORG

Diagnosing and Treating Childhood Movement Disorders

FREE Ask the Expert Teleconference and Web Seminar

http://www.eparent.com

Sept 24, 2002 - 7 PM - 8:30 PM (EDT)
(6 PM CDT, 5 PM MDT and 4 PM PDT)

Featuring:

A. Leland Albright, MD
Professor of Neurosurgery, University of Pittsburgh School of Medicine; Chief, Department of Pediatric Neurosurgery, Children's Hospital of Pittsburgh.

Terence Edgar, MD
Child Neurologist
St. Vincent's Hospital
Green Bay Wisconsin

Open to Families & Caregivers!

Learn how to differentiate between childhood movement disorders and associated symptoms. Additionally, the experts will discuss available treatment options, outcomes and resources for more information. Following the brief presentation, the experts will be available for questions on-line and via telephone hook-up.

EP Exceptional Parent

UCP Understanding Disabilities Creating Opportunities

Medtronic When Life Depends on Medical Technology

Register online or call today to reserve your place:

Sponsored, in part, by an educational grant from Medtronic, Inc.

Register now for FREE

To register visit www.eparent.com or call 800-EPARENT ext. 203. RSVP by: Sept 19th 2002

The events can be easily accessed by telephone and via the Web – through EP's site (www.eparent.com) and the United Cerebral Palsy site (www.ucp.org).

Log on to EParent.com for simple instructions and more details on how to participate.

Circle #51 or visit www.eparent.com/adinfo

continued from page 72

your child desire to and desire not to live, work and spend leisure time as an adult." Look ahead and imagine what your child will enjoy doing, who his or her friends will be, where they will go on vacations and who will make it possible for them to get to those places. It is important not to limit your vision to what other children with similar disabilities are doing, or what people are telling you is possible or likely to happen. "Once you have a dream, you can begin working toward getting the things your child needs," says Tomko. "Let not our needs determine our dreams…but let our dreams determine our needs."

Nancy McElroy is the mother of two daughters with different disabilities. Heather is 31 and has cerebral palsy (CP) and spastic quadriplegia and Shannon, 32, has Down syndrome. Both women live outside the McElroy home and planning for each one was unique. "For us it was obvious that they would need different living arrangements, that one could function and interact completely and independently and the other could not," says Nancy. The McElroys recall when they began to realize that Heather might need more support and care than they could offer her at home. "We took family vacations every year," she explained. "The summer when she was 15, we couldn't get her to the ocean. She was so heavy and there was so much equipment. We had to keep her in the cabana the whole time. Then, one evening, we were giving her a bath, it took both of us, and she began to stiffen up and we almost lost her." Nancy said that it was her school district that approached them and suggested they find a place that could help. The McElroys worked with their district to develop an IEP for Heather and to find a school that could offer her the supports, assistive technologies and other learning tools to address her unique mobility, communication and education needs. She was placed at The Center for Discovery.

The Center for
DISCOVERY

A recent NICHCY report, "Parenting A Child With Special Needs: A Guide to Readings and Resources," states, "it is not possible for parents to imagine all the stops and detours that they will make as their unexpected journey takes them into the future. Advocates believe it is important for parents to have expectations about what their child with disabilities can achieve in the future and to encourage their child to develop as much independence as possible." Once high but realistic expectations are set, each family must consider many factors to determine the best place for the child to develop and practice skills for independent living.

Ellen and Jack Orlando are parents of two girls. Nora, the younger, has Rett syndrome; when she was 15-years-old she was placed residentially at The Center for Discovery in Harris, NY. "The first few weeks were very difficult, but the school was so adept at understanding what we were going through," says Ellen. "Nora adjusted much more rapidly because it was the right thing for her." The Orlandos were able to make the decision about residential placement for Nora without feelings of guilt, because they realized that resources at home would no longer be available to maintain the same high quality of life they had been able to offer her up to that point, "When both children were young, the difference in their abilities and their daily routines was hardly noticeable. But as Sara, our older daughter, matured and Nora grew it became more difficult to balance each one's needs." Like other parents of children with physical disabilities, the Orlandos were faced with the challenge of transporting Nora. "Though friends and family were very supportive, we couldn't ask for much help after Nora moved into early childhood. She was just too big and people weren't comfortable tending to her needs," Ellen explained. A final factor in the Orlandos' decision was that of control. "We wanted to be the ones making the decisions for Nora. Everyone in the family loves her, but not like us."

Planning for the long view is a process of continual change where parents work diligently to find a balance between family wellness and the stresses and battles of securing rich and loving environments in which their child with disabilities can thrive. Dennis Raymond, Admissions Director for The Center for Discovery, a comprehensive center in Harris, NY serving people with disabilities, urges parents to "be prepared to do whatever is necessary to create a placement that best serves the needs of the child and the family. Parents will have to do research, advocacy and may even have to take the legal route. When the child is placed in the right setting, the whole family can thrive."

"It is about finding balance for the entire family," says Joan Kandler, mother of 32-year-old Susan, who was diagnosed with brain damage when she was 8 months old. "Primary caregivers have

Parenting Suggestions

"Becoming a parent for the first time changes our identity forever," says Dr. Robert Naseef, psychologist and author of Special Children, Challenged Parents. "There is a balancing act between caring for the needs of children and putting time and effort into maintenance and growth of ourselves and our relationships. This transition in the development of family life is challenged even further by disability or chronic illness." Here are some of his suggestions for couples who are parenting a child with special needs.

- Communication is key. Resist the tendency to blame; ask for what you need and listen to what your partner needs.
- Add some fun to your life, alone and with your partner. If you worry about leaving your kids, take a beeper or cell phone.
- It helps to be as active as you are comfortable being, in the community as a whole and in the special-needs community in particular.
- Exercise. Almost any form of exercise will lift your spirits if you do something you enjoy and do it regularly.
- Keep a journal. Writing down thoughts, feelings and experiences is helpful in putting things into perspective.
- Support groups. It is often helpful to share experiences, thoughts and feelings with others who are in the same boat and can understand.
- Break problems down into more manageable pieces.
- Remember that you and your partner are both on the same parenting team, not competing.
- Seek professional guidance when necessary. It is not a sign of weakness to seek help. It is wise to think of your needs as well as those of your children.
- Keep in mind that a hard life can still be a good life!

an intuitive sense of when it gets terribly out of sync; you know it and you begin to plan for the next step. When you are doing everything you can, using all the public and private resources available, and the primary caretaker is exhausted, the other children become very demanding of attention, and the child with the disability is not progressing, that's when you know that love is not enough." Joan recalls that she had to "fight tooth and nail" with her husband before he would consider a residential placement for Susan. "His fear was that she would forget us, she wouldn't know her family anymore."

Joan and her husband had months of discussion until they both felt comfortable and agreed on the type of placement they would seek out for Susan. "We wanted a place that was as much like a home as possible, where they would be a family unit and have values similar to ours. We talked and looked for more than a year. Sarah was rejected from several programs owing to the complexity of her disabilities. We finally found a wonderful program, and everything fell back into balance. I would get a sitter for the other kids and I'd visit Susan. I even got a job there so I could see her. The other children would go up and have sleepovers with their sister. It was very friendly and very family-focused."

From Vision to Reality

For many parents, the fears and concern for their vulnerable child are overwhelming, and can prevent parents from taking the basic steps to plan for the future. Special-needs attorney Herb Hinkle of Lawrenceville, NJ states, "There are some things families can control and many they cannot. Often they become paralyzed by the things they cannot control and fail to take care of those they can." Mr. Hinkle likens the process to his experience going back to school for tax law: "There were 600 codes I had to learn; it seemed endless and impossible, but once I got through those that was it, no more." Putting financial and legal papers in order seems like an insurmountable task, but once it's done, it's done. Mr. Hinkle urges families to "stay plugged in" by going to meetings, talking with as many parents as possible, and accessing resources and publications that offer up-to-date information.

There are a few basic steps you can take to ensure your child's quality of life in the future. "I see two distinct issues," says Larry Greenstein, father of a child with disabilities and a CPA in Long Island, NY, "setting up a financial plan and finding a good program for those finances to fund. You have to find a model you like and people you can trust. You visit the places. In some cases you can get a group of parents together and get a house for the kids. There are so many options. My son is only 10; we don't know where he will be at 18 or 20. We operate under the assumption that all the intensive therapies we are doing will get him to a point where he will function on his own. We are on lists for group homes, as some of the waits can be 10 years. If we need it, it is there," Mr. Greenstein explains."

Write A Will and Establish Guardianship

Whether or not you parent a child with a disability, you should have a will that establishes guardianship for your children in the event of your death. In the absence of a will, a judge decides who is best to care for your children. At the age of majority (18 in most states), parents must petition the court to be named as guardians for their children who are deemed legally incompetent. Parents can include siblings and other family members or friends as co-guardians.

Create A Special Needs Trust

Become knowledgeable about the laws and eligibility requirements for the federal and state programs their children will be entitled to as adults. Both Social Security and Medicaid are means tested and requirements change from state to state. If the individual has more than a specified amount of money in his/her name, they can be deemed ineligible for benefits.

continued on page 76

BEST COPY AVAILABLE

continued from page 75

Law currently allows for a Special Needs Trust to protect individuals with disability from risking ineligibility. The trust gives trustees the right to pay for any expenses their children might incur, other than those things covered by the government agencies. The trust prevents monies from flowing through the child in any way, preserving eligibility. All family members and friends should be made aware of the trust so that money is not gifted to the individual. Parents need not avoid setting up a trust because they have no money to fund it. Most trusts are funded by insurance policies that have the child named as beneficiary and are not funded during the parent's lifetime. (See also "Special Needs Trusts" on the Financial Planning page of www.eparent.com.)

Keep Informed

According to Herbert D. Hinkle, who has represented people with disabilities and their families since 1974, parents often overestimate the resources necessary to secure a good quality of life for their adult children with disabilities; this can lead to paralysis. "The more you know, the easier it is," he says. The first, and most important aspect in planning a trust is to remove the economic obstacles that prevent siblings or other family members from being involved. The trust will also specify how money can be spent. It provides for airfare and other expenses to bring the siblings together if they live apart. It can also pay for someone to be the "eyes and ears" and to check up regularly on the individual. In order to set up a plan, you need to be familiar with the laws in your state. Parents should find a good attorney who specializes in disability law and a tax accountant who knows special-needs tax law. A good place to start is with your local ARC, Developmental Disabilities Council or advocacy organizations to obtain referrals.

Begin Transition Planning Early and Be Informed About What's Available

All students receiving special education services under the Individuals with Disabilities Education Act, IDEA, are entitled to transition services beginning at age 14. These services are defined as "a coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to post-school activities." These activities include "instruction, related services, community experiences, the development of employment and other post-school adult living objectives and if appropriate, acquisition of daily living skills and functional vocational evaluation."

Become familiar with this law and the Americans with Disabilities Act (ADA), so you can best advocate for your child. Know when your child will age out of each educational placement and be prepared to push the school and other agencies involved if needed. If your child is 14 and a transition plan is not part of his or her IEP, contact your child study team and the state and community organizations involved with adult and vocational services in your area to create one.

Planning For Independence

When you are developing goals to make your vision a reality for your child consider the following:

- create opportunities for your child to acquire skills now that will make him independent in the future;
- ensure that your child has opportunities to develop social skills that can be used in many settings;
- teach your child to be responsible for personal needs and self-care; and
- encourage your child to develop and practice self-determination and self-advocacy skills. At some point, your child will be his or her own best advocate.

The Dignity of Risk

"There is always a risk in having someone else take care of a loved one, but there is risk in everyone's lives," says Paul Prior, whose brother has autism and is non-communicative. "People with disabilities have the right to experience risk, as well as the rewards that come with it. My brother is placed in a group home and there is risk there, but David has developed skills he had never had. He can sign for food, water, the bathroom and he makes eye contact. We did a great deal of planning and we were able to line up very good adult services. He is more independent now than he has ever been."

continued on page 78

The National Council on Independent Living

When searching for an adult placement for your child, a great place to start is The National Council on Independent Living. There are 160 independent living centers across the US. The centers offer information and referral services, independent living skills training, peer counseling and advocacy. Colleen and Max Starkloff run Paraquad, an ILC in St. Louis, MO. Colleen writes, "Independent living centers were established to change the way our society thinks about and reacts to people with disabilities. Independent living means having control over one's life and making decisions and choices about how one lives based on a reasonable framework of options." The NCIL can answer your questions and refer you to a center in your area.

Photo courtesy of Midland Daily News
EDEN ORGANIC APPLE JUICE
ORIGINAL EDENSOY ORGANIC SOYMILK
EDEN SELECTED OLIVE OIL Spanish Extra Virgin
EDEN ORGANIC Endless Tubes Rigatoni
EDEN ORGANIC Diced Tomatoes with Green Chilies
EDEN ORGANIC LENTILS
EDEN ORGANIC KIDNEY BEANS
EDEN ORGANIC BARLEY MALT
EDEN ORGANIC UDON PASTA

Ⓚ parve

Pure Food our Passion
Great Taste our Joy

Our food is sought out by people worldwide who desire the highest quality, safest, most nutritious, delicious, certified organically grown and produced kosher food. Eden offers over 150 Ⓚ parve, organic foods.

www.edenfoods.com

EDEN®

1053

©2002 Eden Foods, Inc. • Clinton, Michigan 49236 • 1 888 424-EDEN

Circle #41 or visit www.eparent.com/adinfo

Save 50¢
On any
EDEN Product

EDEN®

EDENSOY EXTRA
EDEN ORGANIC GARBANZO BEANS
EDEN ORGANIC Pizza · Pasta Sauce
EDEN ORGANIC

MANUFACTURER'S COUPON | EXPIRES 11 / 30 / 02

Consumer: Coupon good only in USA on purchase of brands / size indicated. Void if copied, transferred, prohibited or regulated. **Retailer:** Eden Foods, Inc. will reimburse you for the face value of this coupon plus 8¢ handling if redeemed in compliance with our redemption policy. Copy sent upon request. Invoices proving purchase of sufficient stock to cover coupons must be shown on request. Face value .001¢. Mail coupon to: **CMS Dept. #24182; One Fawcett Drive; Del Rio, Texas 78840**

Expires: November 30, 2002 **10695**

5 24182 00050 9 (8101) 0 10695 1102

continued from page 76

Mr. Prior, who is now a special-needs attorney and family advocate in Lawrenceville, NJ, looks back on his childhood with his brother. "My parents did their best to protect me from the burden of having to care for him. It is absolutely not a burden and it doesn't take as much of your life as you think. It is important for siblings to know that they are not going to literally be their brother or sister's keeper. There will be no need for the person with a disability to live in a siblings home or be supported financially by the sibling. If you plan properly there is money and a place for the person with a disability to live."

The family members quoted here all agree on one point: that the supports provided by independent-living and residential centers make it possible for their family members to participate much more fully in their community than they would be able to if at home. The McElroys are certain that both their daughters have much more enriching lives being on their own. As Nancy explains, "The biggest thing we've given them is a sense of self...they would not have had that at home with us."

Although the Orlandos believe that a dependable respite program might have allowed them to keep Nora home for awhile longer, they believe that all children need to be off on their own. "Who wants to stay at home all their life?" Ellen asks. "Our typical children spend time picking the right college; the children with disabilities need to find their own neighborhood where they can flourish, too. As they get older, their world becomes smaller and smaller, unless they have access to the tools and resources to go out into the typical world. Living with us would be very restrictive for Nora. For her, this is the least restrictive environment."

"Parents should remember that even if you make critical mistakes along the way, things have a way of working themselves out, " says Paul Prior. "We never could have imagined such a spectacular program for David, in an integrated community. He takes better vacations than I do! He has a very fulfilling life."

WHAT PARENTS CAN CONTROL:

- Where resources will go.
- Preservation of eligibility for state and federal assistance programs through the creation of a special needs trust.
- Ensuring that family members are not financially or emotionally burdened, by planning ahead, making a will and establishing guardianship.
- Enhancing the individual's quality of life by providing resources for special activities, vacations, visits with siblings and other personal things.

Resources

The National Council on Independent Living, 1916 Wilson Boulevard, Suite 209 Arlington, VA 22201. Phone: 703-525-3406. Web site, www.ncil.org.

The Discovery Center's International Family Institute sponsors the Family Information Exchange Project, which offers a research and education library, family programs and training series and a family wellness program. Call 1-845-794-1400, ext. 1842 or visit the following web sites: www.discoveryifi.org or www.thecenterfordiscovery.org.

The Office of Special Education and Rehabilitative Services (OSERS), part of the US Department of Education, is committed to improving results and outcomes for people of all ages with disabilities. Their web site, www.ed.gov/offices/OSERS, covers information on special education and adult services programs, the President's new Freedom Initiative and many valuable links.

The ARC of the United States; 1010 Wayne Ave., Suite 650, Silver Spring, MD 20910. Phone: 301-565-3842. Web site: www.thearc.org.

You can contact Mr. Hinkle or Paul Prior in NJ at (609) 896-4200 or in Pennsylvania at (215) 860-2100. Or visit their web site at www.hinkle1.com.

Other Resources for Special Needs Estate Planning:
SNAP- They make Special Needs Estate Planning a SNAP! This is a wonderful organization headed by parents of two special needs children. Contact them at: West Coast: 310-201-9614, 888-310-9889; East Coast 973-236-9887 or 877-348-6497. Web site: www.snapinfor.org.

Important Web Sites:
I Can! Brings together content, community and resources in one place that is easy to navigate and welcomes your input. www.ican.com.

National Council on Disability: www.ncd.gov

NICHCY is the national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. Look for their Transition Summary, TS10, January 1999. www.nichcy.org. "Parenting A Child With Special Needs: A Guide to Readings and Resources."

Kids Together Inc., www.kidstogether.org, is a non-profit organization co-founded by parents and organized by volunteers. Their mission is to remove the barriers that exclude people with disabilities. The site offers helpful information and resources to enhance the quality of life for children and adults with disabilities and communities as a whole.

The EP web site, www.eparent.com, offers access to material from past issues of EP Magazine.

BEST COPY AVAILABLE

www.abilitiesexpo.com

EXPO

New England
Bayside Expo Center
September 20-22

Northern California
San Mateo County
Expo Center
November 22-24

Education and
Equipment to
Empower.

Come **sample products** and **talk one-on-one** with service providers. As our guest you can attend **complimentary educational workshops** on everything from better sex to better jobs. Or perhaps you would like to see the power of new technologies in our **Access Ability Pavilion.** There are many options for you at **Abilities Expo.**

For more information please call (800) 385-3085 or (218) 723-9130 outside of the USA.
www.abilitiesexpo.com

abilities EXPO

PRESENT THIS COUPON FOR FREE ADMISSION

[ADMIT ONE]

Bring coupon to any **2002 Abilities Expo** and save the $5 on-site registration fee.
Coupon must be filled out to be valid and may be photocopied for additional registrants.

NAME: ______

ADDRESS: ______ 1055

CITY: ______ STATE: ______ ZIP: ______ 10

For information call:
(800) 385-3085
(218) 723-9130 (outside USA)

Produced and Managed by:
ADVANSTAR COMMUNICATIONS

All events are wheelchair accessible.

© 2002 Advanstar Communications Inc. All rights reserved.

Circle #17 or visit www.eparent.com/adinfo

STEROID USE in the Neonatal Intensive Care Unit:

A Preventable Cause of Cerebral Palsy and Developmental Delay

by Andrew Unger, MD

Each year some 40,000 infants in the United States are born more than ten weeks prematurely, that is, after a pregnancy of less than 30 weeks in length. Just 20 years ago, the majority of such newborns died shortly after birth, usually because their lungs were too immature to allow them to breathe effectively. Now, at least 80 percent of extremely premature infants survive to hospital discharge. Those that do perish most often succumb in the first week of life, from strokes, infections and birth defects. Death from the typical lung disease of prematurity—Hyaline Membrane Disease (HMD) or Respiratory Distress Syndrome (RDS)—has become quite rare.

The reasons behind this dramatic improvement in the outcome of preemies with HMD/RDS are important to understand, because the improvement in survival has not been associated with a reduction in the rate of brain damage among the survivors. Many extremely premature infants (perhaps 20 percent, or some 6,000 to 7,000 per year in the US) have either developmental delay (DD) or cerebral palsy (CP). Recently, we have learned that some of these disabilities may be preventable by avoiding administration of a drug, dexamethasone, once commonly used in neonatal intensive care units (NICUs). Understanding this requires an overview of the entire subject of DD and its relationship to extreme prematurity.

Extremely premature babies are not just "small" or "early." They're not ready yet. None of their organ systems function as they should. Starting at the top, almost all of the complex pattern of hills and valleys of the cerebral cortex—the thinking part of the brain—are not even visible in the brain of a 26-weeker. Should such an infant come to autopsy, her brain will look as smooth as a cue ball, split just once down the middle and once on each side. The connections that form the thinking part of the brain, connections designed to develop in the dark, warm, wet, pain-free environment of the uterus, now must develop in a bright, dry, painful NICU. The chances for abnormal development are high.

Inside the premature brain, blood vessels in the ventricles—the fluid-filled chambers where spinal fluid is made—are present that would later shrink and disappear naturally, if the pregnancy were to last until the eight month. Prior to that, these vessels, which are thin-walled and not designed to withstand large changes in blood pressure, may burst and cause strokes. Moreover, the blood supply to the brain surrounding these ventricles, the periventricular white matter, is tenuous. Damage to the periventricular area, often caused by low blood pressure or infection, can cause CP.

Premature lungs are both stiff and sticky. In particular, they lack surfactant, the natural lubricant that keeps the walls of the little air sacs where gas exchange occurs from sticking to each other at the end of expiration. If premature labor is detected early enough to allow delivery to be delayed by a few days, the expectant mother may receive two doses of a particular steroid, betamethasone, that induces the fetus to make surfactant. Often, this minimizes the severity of the subsequent HMD/RDS. Of note is that this particular steroid is given briefly to the mother, not to the fetus directly, and rarely more than once.

Surfactant is available as a medicine to be given directly into the newborn's lungs, and better ventilators have been developed that allow gas exchange to occur in the face of severe disease. The problem of premature lungs sticking to themselves internally has basically been solved, so most extremely premature infants now survive their initial lung disease.

After the HMD/RDS has resolved, however, these immature lungs still contain far more connective tissue than adult lungs. They are stiffer—like sponges instead of balloons. Extremely premature infants will often require continued respiratory support (a ventilator or continuous positive airway pressure) for one to six weeks after their initial lung disease has resolved, until the Chronic Lung Disease (CLD)—a developmental phase in which the connective tissue "clears out" and the air sacs grow—improves. During this phase, optimizing nutrition and avoiding hospital-acquired infections facilitates more rapid lung growth.

Let us turn our attention to the premature infant's gut, and the problems of nourishing such a tiny baby. Until approximately 32 weeks gestation, the gut does not move food forward from mouth to anus with any degree of regularity. Not only do premature babies not know how to swallow, but their stomachs don't empty well, their small bowels don't digest well and their colons don't excrete well. Food just seems to slosh around. At a time when human brain growth is supposed to be at its most rapid, the period from 24 to 30 weeks gestation, the fuel for that growth is difficult to process postnatally.

While it is beyond the scope of this article to describe particular methods of encouraging adequate nutrition in the NICU, some generalities may be stated. Early initiation of small volume feedings coupled with aggressive intravenous nutritional support in the first week or two of life, followed by rapid advances in feed volume once the gut "wakes up," seems ideal. Such an approach has its risks—a life-threatening bowel infection called necrotizing enterocolitis may occasionally occur—but these risks are outweighed by the benefits, and can be minimized particularly by feeding the baby his own mother's milk. Necrotizing enterocolitis is much less common in breast-fed newborns. In addition, a rapid transition away from IV nutrition minimizes the risk of blood infection from the intravenous lines themselves.

continued on page 82

"School" brings special challenges for a child with special needs

With over 40 years of assisting the child with special needs and his/her family we can offer:

- **Preschool Programs for the Child, age 3 to 5 with:**
  Mild to Profound Developmental Delays, Sensory and Communication Delays, and Hearing Impairments
- **School Program for the Child, age 3 to 21 with:**
  Multiple Developmental and/or Medical Needs including Acquired Brain Injury
- **We Offer All Students:**
  Small Classes with 210-day Caldenar
  On-site Nursing Services
  Assistive Technology
  Customized Adapted Equipment
  Augmentative Communication
- **We Offer All Families:** *(enrollment in school not necessary)*
  Comprehensive Audiological Services
  Family Support Resources (toy library, parent networking & referral, and more)

Call (203) 386-2743 for more information

FEROLETO Children's Development Ctr.
95 Merritt Blvd., Trumbull, CT 06611
www.stvincentsspecialneeds.org

St.Vincent's
Special Needs Services

Circle #80 or visit www.eparent.com/adinfo

1057

continued from page 81

To summarize: premature infants are at risk of brain damage because of environmental stress, strokes, particularly vulnerable brain tissues, malnutrition and infection. Until the NICU can more closely resemble a uterus (and efforts to reduce environmental stress are underway), or until premature birth itself can be prevented, some premature infants will inevitably be at risk for serious developmental delay. Doctors have just learned, however, that one of the medicines in common use in NICUs increases that risk markedly.

Let us return to chronic lung disease, CLD, the state of the premature lung after the initial HMD/RDS has been treated with surfactant. Lungs with CLD are stiff; the preemie with CLD may be too weak to move enough air to survive. We know this stiffness will lessen over the course of weeks of patient attention to nutrition and avoidance of infection. In the meantime, though, the infant must be attached to a breathing machine—an uncomfortable life for both the baby and her parents. In addition, correct respiratory support is labor-intensive, expensive, and risky in its own right, predisposing to pneumonia and trauma to the airway. All these risks, too, can be minimized, but only if there are enough experienced nurses to allow for constant and careful observation of every infant.

In the early 1990s a serious nursing shortage developed in the United States. At the same time, hospital reimbursement for the care of premature infants declined, as HMOs and other third-party payers pressured physicians to shorten lengths of stay. If the duration of chronic lung disease could be shortened, money could be saved and, perhaps, outcomes improved. A drug to treat CLD was needed.

An old medical aphorism states that "in times of desperation atheists turn to God, and doctors turn to steroids." Pediatricians already knew that, given prenatally, steroids could help prevent HMD/RDS. Why, then, not try steroids after birth to treat chronic lung disease? In fact, there was every reason to think that dexamethasone—a powerful synthetic steroid that reliably loosens up connective tissues—might improve CLD. That dexamethasone treatment also causes high blood pressure and ulcers and predisposes to fungal infection may be true, but we have other drugs to treat those complications. That dexamethasone also stunts growth—well, that is the tradeoff for keeping the premature infant alive. So dexamethasone was tried, and it worked. A few days of steroids and many ventilator-dependent infants can come off their machines. Their parents can hold them more easily, their sore mouths and noses heal, they can learn to eat earlier, and then, perhaps, even go home sooner. Parents are happier. Money is saved.

The problem is that premature infants treated with steroids are approximately twice as likely to have DD or CP as those not treated. No drug can treat that period of stunted growth the steroids cause. Developmental delay in the premature infant is usually the result of many cumulative insults. Harsh environment, inadequate nutrition, and infection all may contribute. Steroid treatment of CLD seems, often, to be the final straw.

The data are new, and still somewhat controversial, but most neonatologists, the American Academy of Pediatrics and the Canadian Pædiatric

HDIS

Convenient Home Delivery of Bladder Control Products

Try our Attends® Youth Brief, FREE!

Reliable protection that fits like regular underwear!

FREE Sample Offer!

- Ideal for children weighing 35 to 75 pounds.
- Four refastenable tapes provide an adjustable fit.
- Stay-Dry lining keeps moisture away from the skin.
- Wetness indicator lets you know when the brief needs to be changed.

Call now for a FREE sample!

1-800-2MY-HOME®

(1-800-269-4663)

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

"We're happy to answer any questions you have."

- *Mary*

©2002, HDIS 024-133

Circle #47 or visit www.eparent.com/adinfo

Society now accept them. From the February 2002 issue of *Pediatrics:*

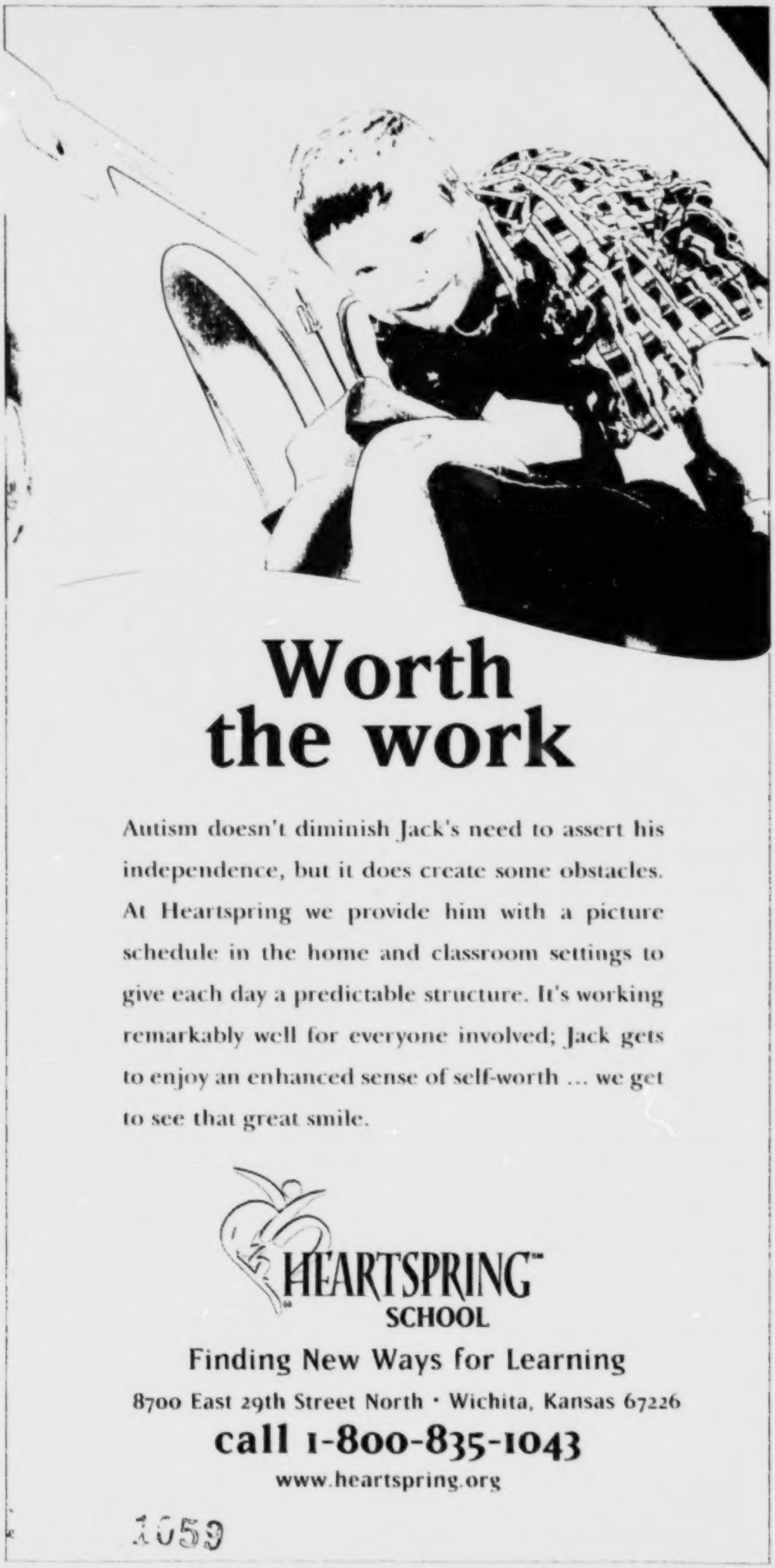
"On the basis of limited short-term benefits, the absence of long-term benefits, and the number of serious short and long-term complications, the routine use of systemic dexamethasone for the prevention or treatment of CLD in extremely premature infants is not recommended. ... Outside the context of a randomized, controlled trial, the use of corticosteroids should be limited to exceptional clinical circumstances (eg, an infant on maximal ventilatory and oxygen support). In those circumstances, parents should be fully informed about the known short- and long-term risks and agree to treatment."

An old medical aphorism states that "in times of desperation atheists turn to God, and doctors turn to steroids."

In short, while dexamethasone does help get preemies "off the ventilator," that small benefit is not worth the long-term risk.

So how was is it that perhaps one-third of extremely premature infants born in the US in the 1990s were treated with a drug that we now learn may cause DD and CP? The answer is simple: only large, long-term studies, many just completed, could reveal the added risk. Individual neonatologists rarely

continued on page 84



Worth the work

Autism doesn't diminish Jack's need to assert his independence, but it does create some obstacles. At Heartspring we provide him with a picture schedule in the home and classroom settings to give each day a predictable structure. It's working remarkably well for everyone involved; Jack gets to enjoy an enhanced sense of self-worth ... we get to see that great smile.

HEARTSPRING™
SCHOOL
Finding New Ways for Learning
8700 East 29th Street North • Wichita, Kansas 67226
call 1-800-835-1043
www.heartspring.org

Circle #22 or visit www.eparent.com/adinfo

1059

> **As is often the case, a promising treatment only later has been shown to have serious, unanticipated side effects.**

continued from page 83

treat NICU graduates beyond a few months after discharge. Low IQ and cerebral and motor delay are generally diagnosed after the baby is one year of age. As is often the case, a promising treatment only later has been shown to have serious, unanticipated side effects.

What, then, can we learn from the data regarding post-natal steroid use in the premature infant? As of 2002, we know that such treatment should be restricted to those rare, life-threatening cases of CLD that may, on occasion, occur in the tiniest and sickest of preemies. More important, however, parents and professionals alike must learn to accept better the dual nature of modern neonatal care.

For the first few days of life, most extremely premature infants are critically ill—so sick they may die. Almost any intervention is justified in order to keep the baby alive. After the crisis has passed, however, aggressive interventions are more likely to harm than help. The rest of a tiny preemie's hospitalization must be focused on growth, establishing good nutrition and avoiding infections. The change in emphasis—for parents, for doctors, for nurses—is both necessary and profound. Patience, not action, becomes a virtue. Less truly becomes more.

Regardless of how they are cared for, many infants born after pregnancies of less than 30 weeks will have handicaps and some, tragically, will die. We can minimize the suffering of the survivors only by remembering what our grandmothers knew:

Babies need to be kept warm and clean. They need to be held and well fed. And once a baby is growing, only rarely does it need strong medicine. EP

NEVER GIVE UP THE SEARCH TO FIND THE RIGHT PLACE...

"I was advised to settle for something less, but kept searching. When I visited Crotched Mountain there was a tangible difference in attitude– a professionalism, respect, and "can-do" attitude that set them apart. Standards are high and the approach genuine–they really care! I am very happy with Crotched Mountain and most importantly, so is my son Jared. He has grown enormously in many ways and is becoming the young man that I always thought he could become. It's a family's dream, come true!" —*Kathy Berns*

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

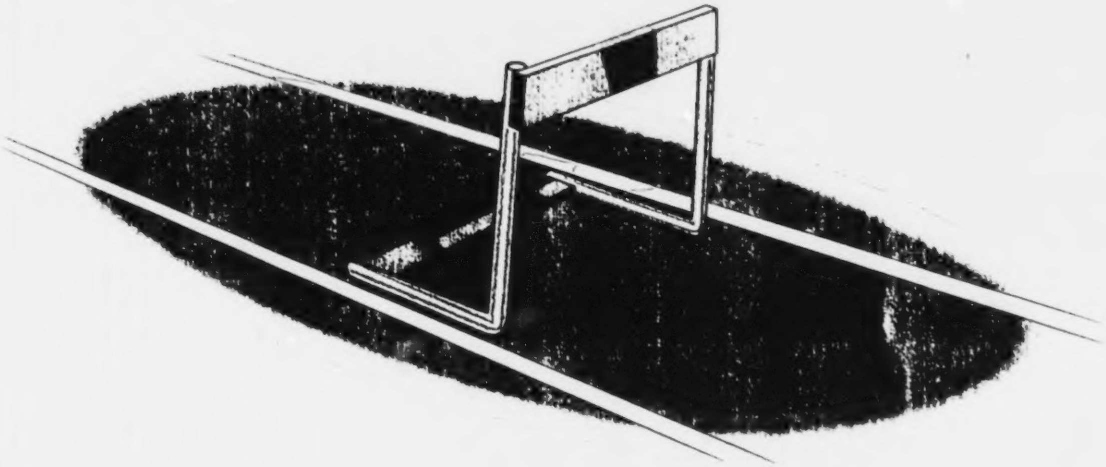
For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@crotchedmountain.org

OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES
CROTCHED MOUNTAIN

Circle #36 or visit www.eparent.com/adinfo

1060

Coordinating your child's care shouldn't be another hurdle.



Neurological evaluations. Educational consultations. Behavioral therapy. We understand how frustrating and confusing meeting your child's special needs can be. That's the idea behind Bancroft NeuroHealth's **Center for Children and Families**. The Center's team of medical and clinical professionals offers a variety of cutting-edge interdisciplinary evaluation, treatment and planning services for children with complex medical, behavioral and special education needs — **all under one roof**.

Services include medical consultation; neurology clinics; developmental pediatrics; rehabilitation services such as occupational therapy, and speech and language therapy; early intervention programs; chronic disease services; behavioral health school consultation; home-based services; and family support and education.

You face enough hurdles in your life: getting the best care for your child shouldn't be one of them.

For more information, call or write:

1-800-774-5516

Hopkins Lane, P.O. Box 20
Haddonfield, NJ 08033-0018 USA

www.bancroftneurohealth.org

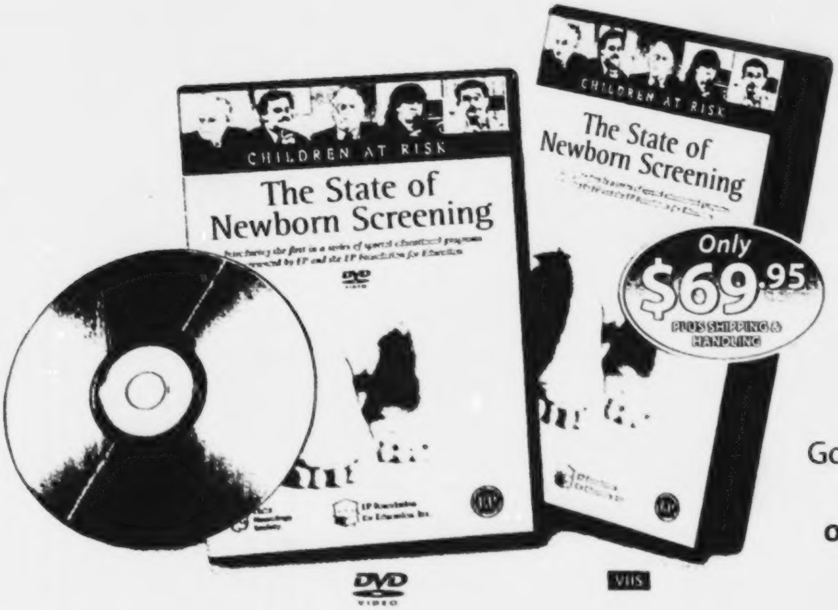
Bancroft NeuroHealth, a New Jersey Non-Profit Corporation

Bancroft
NeuroHealth

Circle #23 or visit www.eparent.com/adinfo

What is Universal Newborn Screening?

This could help change the
quality of your child's life



EP Foundation for Education, Inc.

Child Neurology Society

Go to: www.eparent.com
for more information

ORDER THE DVD NOW!

Darryl DeVivo, MD SIDNEY CARTER PROFESSOR OF NEUROLOGY COLUMBIA UNIVERSITY	*Piero Rinaldo, MD, Ph.D.* DIRECTOR, BIOCHEMICAL GENETICS LABORATORY MAYO CLINIC	*Edwin Naylor, Ph.D.* PRESIDENT NEOGEN SCREENING, INC	*Joan E. Pellegrino, MD* ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES UMDNJ, ROBERT WOOD JOHNSON MEDICAL SCHOOL	*Paul M. Fernhoff, MD* MEDICAL DIRECTOR EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #52 or visit www.eparent.com/adinfo

Sharing the Caring

Sally, 40 lbs. and 45" tall, in the #8600 Reclining Bath Chair with #8875 Head Pad

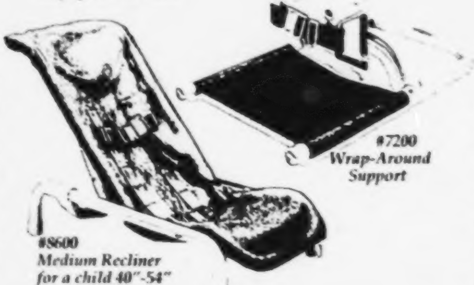
Columbia offers you solutions to the daily challenges of bathing, toileting and transporting your child – *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

■ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.

#5800 Hi-Back Positioning Commode for junior adults

■ At bathtime, our popular **Wrap-Around Bath Supports** and **Reclining Chairs** allow your child – and you – to enjoy the bath.



#7200 Wrap-Around Support

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

■ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.–yet weighs only 11 pounds! Comfort, style and adjustability have made it the No. 1 choice since 1986.

#2000 Car Seat

Why do these products work so well?

Much thought and care go into the design of each Columbia product. We make each item in the **right size for your child,** with lots of adjustability for a custom fit. They are made of durable materials, proven in real life. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

COLUMBIA
SHARING THE CARING

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG
Columbia Medical Mfg. Corp., Dept D2, P.O. Box 633, Pacific Palisades, CA 90272
Visit our web site at http://www.ColumbiaMedical.com

Circle #32 or visit www.eparent.com/adinfo

HOME DELIVERY!

Connetquot West, Inc.
Health Care Products

Pressure Management
Nutritional/Enteral
Specialty Seating
Bathroom Safety
Personal Care
Incontinence
Ambulatory
Respiratory
Urological
Beds/Lifts
Skin Care
Mobility

This month's
FREE SAMPLE FEATURE
Resource Just for Kids
CALL FOR YOURS!

Quality for You. Quality for Life.™

Toll-Free: 866-588-3888

Fax Toll Free: 866-588-3337

711-8 Koehler Avenue ◦ Ronkonkoma ◦ New York ◦ 11779
Email: connetquot@aol.com

Circle #33 or visit www.eparent.com/adinfo

Loneliness shouldn't be a side effect of your child's disability.

At Cotting School, boys and girls of all ages and abilities receive countless opportunities to make friends . . . in the classroom, on a field trip, during basketball practice or in physical therapy. As self-esteem increases with each new friendship, talent and personality shine.

OPENINGS FOR YOUNG PEOPLE FOR 2002 – 2003
NEW POSTGRADUATE RESIDENTIAL PROGRAM NOW OPEN

Cotting School—
where your child belongs.
For information or a tour, please call
Janine Brown-Smith at (781) 862-7323.
www.cotting.org www.cottinghopehouse.org

Cotting
SCHOOL

Cotting School is a 766-approved day school in Lexington, MA for children and youth ages 3-22 with physical, communication, and other challenges to learning.

Circle #35 or visit www.eparent.com/adinfo

SHALEIGH

Shaleigh is two-and-a-half years old and a happy, loving, identical twin. She was born with hydrocephalus, caused by an intraventricular hemorrhage, which now requires her to have a VP shunt. Shaleigh also has cerebral palsy and is legally blind. Her speech is limited to "Hi!" She warms anyone up with her darling little smile. She loves *Barney*, music, her Raggedy Ann doll and spending time with her Mom, Ronda, older brother Shane and twin Sage.

PAYTON

Payton Perkins is two years old and was born five-and-a-half weeks early. He has had ten surgeries along with a number of small procedures. Payton went through physical, speech and feeding therapy and uses a G-tube. He is a very smart, loving and funny boy who has won several contests despite his health. He is his mother Wendy's "miracle child," and his dream is to one day go to Walt Disney World.

BEST COPY AVAILABLE

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (Exceptional Parent), 65 E. Route 4, River Edge, NJ 07661. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your

SA064

ALLISON

Allison Bleeker, 7, is seen here feeding the chickens during the summer and loving every minute of it. Allison has spina bifida, hydrocephalus and a seizure disorder. She has received special services through her school district since she was three months old. She is a happy little girl who loves to hug, play hide-and-seek and wrestle with her dad and sisters. Allison also enjoys books, *Mr. Rodgers*, *Barney* and shopping. She lives at home with her sisters, Amy and Kirsten, and Mom and Dad, Doug and Carolyn.

ISABELLA

Isabella DeBrevi, 16 months, is seen here playing with big brother **Alessandro**, 3. Not only is he her brother, but he is also her best friend who always tries to motivate and encourage her. Isabella has Down syndrome and attends the LeeAnn Britain Infant Development Center, where she receives speech, physical, occupational and music therapy. Her entire family loves the beautiful smile she wears and are very proud of their "little star."

BEST COPY AVAILABLE

child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you would like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

0 01065

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL

4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601

John P. Stewart, M.D., Resident Physician

Phone 502-227-4821

www.stewarthome.com

Circle #81 or visit www.eparent.com/adinfo

WenzeliteRehab

Providers of Pediatric Rehab Equipment

SEATING SYSTEMS
BATHING CHAIRS
STROLLERS
STANDERS
WALKERS

CALL US AT

718-768-8002 / (800) 706-9255

For information about our

FREE EVALUATION PROGRAM

www.wenzelite.com • e-mail: wenzelite@aol.com

Circle #89 or visit www.eparent.com/adinfo

New York Yankee Manager, Joe Torre with TSA member Joriel Sharp.

The National Tourette Syndrome Association

By Judit Ungar and Fred Cook

A truly grassroots organization, the Tourette Syndrome Association (TSA) was founded in 1972 by a small group of people from affected families sitting around a kitchen table in Queens, NY. Today, with a network of 45 state chapters and hundreds of local support groups across the US, the organization hews to its three-pronged mission of *individual and family service, professional and public education and research.* Along with a 25-member volunteer board, world-class medical and scientific advisors help distinguish TSA as the only national, voluntary non-profit membership organization dedicated to identifying the cause, finding the cure and controlling the effects of Tourette syndrome (TS).

Named for the French neurologist Georges Gilles de la Tourette, who first described the disorder in 1885, TS is an inherited neurobiological disorder marked by involuntary twitching and vocal tics that affects more than 200,000 Americans. Many more people are believed to manifest associated behaviors such as attention deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). As a spectrum disorder, TS varies in severity from very mild to quite severe. However, most cases can be categorized as mild.

A diagnosis of TS can be made by observing symptoms and the history of their onset. There is no blood analysis or neurological testing available to diagnose TS. Key symptoms include multiple motor and vocal tics, the occurrence of tics many times a day for more than one year, a waxing and waning of tic severity and onset before age 18. Genetically, males are three to four times more likely to have TS than females.

When necessary, moderate to severe tics can be controlled with medications such as Haldol, Catapres and Orap. Contrary to years of sensationalized media accounts, coprolalia, or the involuntary uttering of obscenities or inappropriate language, is one of the rarest symptoms of TS and is present in fewer than 15 percent of all people with the disorder.

While the exact cause of TS remains unknown, considerable evidence points to the abnormal metabolism of brain chemicals called neurotransmitters. Although there is currently no cure, the lifelong disorder, which affects all races and ethnic groups, is not life-threatening or degenerative and does not affect intelligence or life span. TS symptoms have also been shown to decrease in adulthood.

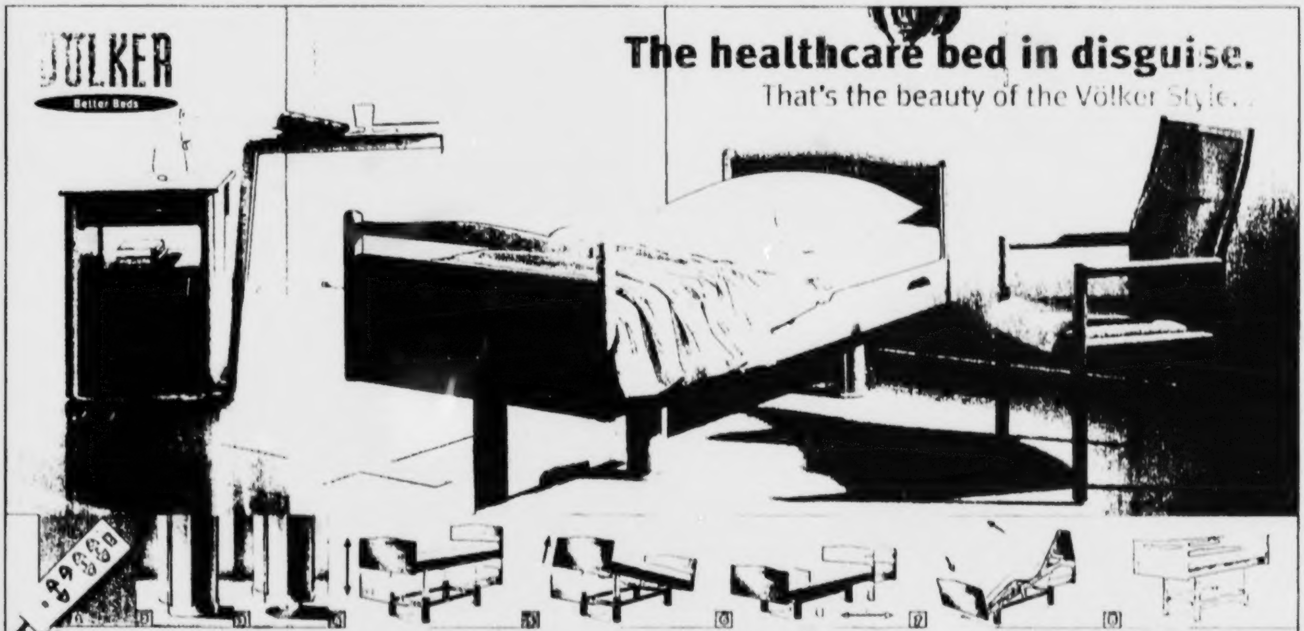
Each day, the TSA responds with compassion and support to hundreds of phone, e-mail and written inquiries from people across the nation and around the world who seek answers about Tourette syndrome. While providing general information about the disorder, the association also assists people with research on significant issues and new treatments, locates advocacy groups, special schools and camps and distributes comprehensive lists of TS physicians, allied and clinical professionals and legal advocates.

TSA also distributes an informative quarterly newsletter to more than 40,000 people that contains the latest information on treatment, research programs and scientific discoveries; publications for children and their families, including a new children's newsletter; and an annual medical letter sent to medical and scientific professionals. Moreover, TSA's extensive catalog of hundreds of publications and dozens of videos helps serve the needs of persons with TS, their communities and the professionals who care for them. Many of the organization's publications and videos offer valuable medical advice and guidance and, as well, seek to reinforce a recurrent TSA theme: that most people with the disorder can lead productive lives and, in many cases, attain high levels of achievement.

Although the public's awareness of TS and its symptoms has steadily increased over the years since the organization's founding, reducing stigma and promoting further public awareness and understanding remains a primary objective. To this end, the association continues to place radio/print/television public service announcements in media outlets across the nation while maintaining a toll-free hotline and a newly revamped website (see information on page 93). Last year, TS was a featured topic on "the Oprah Winfrey Show" and the subject of countless national newspaper, magazine, radio and television stories.

Fostering acceptance and tolerance for people with TS is part and parcel of TSA's educational mission. The association accomplishes this through national,

continued on page 92


VÖLKER
Better Beds
The healthcare bed in disguise.
That's the beauty of the Völker Style.
1
2
3
4
5
6
7
8

1. Electric operation via a hand control or nurse console (optional). 2. Absolutely secure braking. 3. Electric push button casters. 4. Stable height adjustment 15 1/2-31 1/2" (13 3/4-27 1/2" optional). 5. Trendelenberg/reverse Trendelenberg (optional). 6. Easy to move on disappearing casters. 7. Tilt-in-space positioning that allows for sitting (cardiac) or reclining chair. 8. Disappearing full lenght side rails.

For more information call 1-800-321-4240

Hertz Supply Co., Inc. · 4670 Schantz Rd., Suite A · Allentown, PA 18104 · www.hertzsupply.com

Hertz SUPPLY

Circle #49 or visit www.eparent.com/adinfo

1067

L to R: TSA president, Judit Ungar, 13-year-old TSA member Joriel Sharp and his mother, Esther.

continued from page 91

regional and local conferences and the development and dissemination of educational programs for both the professional and lay communities.

Local TSA chapters support the work of the organization by creating 24-hour information phone lines, organizing and coordinating educational and medical conferences and teaching educators about TS and how best to work with students with the disorder. Together, chapters and support groups provide socialization opportunities for adults, families and children affected by TS in an environment of complete acceptance and tolerance.

An excellent example of just such an environment is TSA's biennial National Conference, to be held in Alexandria, VA from October 31 through November 3, 2002. The Conference brings together members of the TS community and their families, educators, TS advocates, physicians, researchers, allied professionals and TSA staff members to interact, socialize, share ideas, discuss issues of concern, learn from experts and, in many instances, meet face-to-face for the first time.

TSA's government relations efforts seek to educate lawmakers, federal agencies and the public about the impact of legislation, regulatory actions and public policy on the health and well-being of people with TS. Two recent government relations successes were the inclusion of TS in the Children's Health Act of 2000 as a disorder to be supported by the federal government, and TSA's naming in the Senate Appropriations Bill of 2001 for possible funding of its healthcare professionals training program. Recent efforts have also focused on garnering support for renewal of the Individuals with Disabilities Education Act and for Mental Health Parity legislation.

TSA's development and special events efforts both raise needed funds to support the vital work of the association and assist in raising the association's profile. TSA coordinates major dinner functions on the east and west coasts, concerts, golf outings, and sweepstakes. TSA also provides technical support to chapters that are in need of assistance in their own fund-raising initiatives.

TSA has been involved in virtually all of the major research conducted on TS. Since 1984, TSA has directly funded research in a variety of TS-related fields, from behavioral neuroscience and neuroimaging to epidemiology and pharmacology. TSA established the Brain Bank

Specially trained dentists and custom facilities are desperately needed in New Jersey to treat individuals with physical disabilities, such as cerebral palsy, muscular dystrophy, spina bifida, and Lesch-Nyhan disease.

The Delta Dental Plan of New Jersey Foundation is partnering with Matheny School and Hospital to create a new, state-of-the-art dental facility to improve access to dental care. This initiative is part of Delta Dental's mission to promote and assist educational projects devoted to the enhancement of dental health and research programs designed to increase public awareness of the general benefits of good health, and to improve dental health through the science of dentistry. For more information about the Matheny School and Hospital dental facility, call (908) 234-0011, ext. 231.

Dr. Gerald Sydell
Chairman, Delta Dental Plan of New Jersey and
Vice President, Delta Dental Plan of New Jersey Foundation, Inc.

Matheny
School and Hospital
www.matheny.org

DELTA DENTAL
Delta Dental Plan of New Jersey Foundation, Inc.
www.deltadentalnj.com

Circle #63 or visit www.eparent.com/adinfo

Program in 1985 to help facilitate the donation, storage, and distribution of rare brain tissue samples to encourage the brain chemistry investigation that is so important to TS research.

In 1999, TSA's International Genetics Consortium heralded a major breakthrough in TS research when it announced the discovery of two small pieces of the human genome that may be strongly implicated in causing TS, and four additional regions that may contribute to it. The discovery was hailed by the scientific community as a major breakthrough that can help point TS researchers in the right direction to locate the TS gene.

In 2000, the National Institute of Health helped to buoy TS research when it awarded an unprecedented, multi-million-dollar five-year grant to TSA. The grant, usually reserved for research centers associated with universities, was the first of its kind to be given to a family-oriented, voluntary health organization.

As the only national voluntary group devoted solely to serving the Tourette syndrome community, the Tourette Syndrome Association looks ahead to a future filled with promise and a deepened resolve to fulfill its original mission: individual and family service, professional and public education and relentless TS research. EP

Judit Ungar is the president of The Tourette Syndrome Association and Fred Cook is the association's chair.

TSA Contact Info:
Tourette Syndrome Association
42-40 Bell Blvd.
Bayside, NY 11361-2820
Phone: 888 4 TOURET (toll free)
718.224.2999
Fax: 718.279.9596
Email: ts@tsa-usa.org
Web site: http://www.tsa-usa.org

Enjoy the out-of-doors together with a

CycleTote® Bicycle Trailer
Running Stroller

1-800-747-2407 www.cycletote.com

Satisfaction Guarantee/Lifetime Warranty

With the Creepster Crawler, You Can Watch Your Child Crawl for the First Time!

Children lacking head control, the ability to roll over or belly crawl have gained mobility with the ***Creepster Crawler.*** Using this light, innovative device, hundreds of children around the world are crawling, working more productively with their therapists, and gaining a head start to more advanced mobility in the future.

The ***Creepster Crawler*** is an ideal solution for youngsters with debilitating conditions such as ☐ Spina Bifida ☐ Down Syndrome ☐ Cerebral Palsy ☐ TBI, and ☐ developmental delays. Children with tracheostomies and G-Tubes also are successful users of the ***Creepster Crawler***.

The ***Creepster Crawler***'s frame has a padded platform that can support a parent or therapist from above, making it easier to work with the child on weight-bearing, weight-shifting, reaching and creeping. Front shoulder, chest and rear straps can be adjusted for individual fit.

Please visit our Worldwide Web site at www.redbarn-enter.com for additional details and a video demonstration of the ***Creepster Crawler***.

Call for a Brochure!
1-800-577-1317
Fax: 1-602-242-9211
or email us at info@red-enter.com

RedBarn
ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.redbarn-enter.com**

CAUTION: Children should not be left unattended in the Creepster Crawler

1069

Circle #75 or visit www.eparent.com/adinfo

Keeping kids safe on the Internet

by Sheryl Burgstahler, PhD

When you think of the wide range of potential dangers on the internet, it's easy to feel helpless and consider prohibiting its use entirely. Unfortunately, there is no foolproof way to protect our children from all of the dangers they may encounter, on the internet or anywhere else.

For my 12-year-old son, the internet is just one more place to find interesting things to do—chat with his cousin in Minnesota, check out the baseball cards available on EBay, look for a new swimsuit at Old Navy or cruise for new computer games. It all seems innocent enough. But, like many parents, I worry about who my son might meet on the net and what inappropriate materials he might encounter on his journeys through cyberspace. Although the vast majority of internet resources and communications are not harmful to children, and reports of child abuse that involve the use of the internet are rare, our kids might stumble into situations or actively participate in communications of which we would not approve. On the net, they might:

- Become exposed to materials that include content that is sexual, violent, hateful or otherwise inappropriate for children.
- Be exposed to communications that are harassing or demeaning and, perhaps, even be drawn into these types of conversations themselves.
- Be encouraged to participate in activities that promote prejudice, are unsafe or are illegal.
- Meet a child predator who uses the internet to develop trusting relationships with kids and then arranges to meet them in person.
- Make purchases using your credit card number.Keep in mind that children can unintentionally encounter objectionable material, so be sure not to blame them if they do. Such materials can be found by innocently searching for information with a search engine, mis-typing a web address, or stumbling into an adult-oriented chat room or bulletin board. For example, children may encounter web sites designed for adults that have articles, pictures and videotapes of a sexually explicit nature; site owners may make little or no attempt to restrict access to adults.

Teenagers are particularly vulnerable to being exposed to material and engaging in activities that are inappropriate. This is because they are more likely than younger children to use computers unsupervised, have the skills and interests to do searches, participate in discussions through email, chat, or bulletin board systems where inappropriate communications can occur, and have access to credit card information.

Clues that your children might be engaging in inappropriate activities include excessive use of the internet, particularly when you are not home or when you are sleeping. Another clue is if they seem uncomfortable when you ask about activities they are engaging in on the net or when you walk near their computer screen. Withdrawal from family and friends and lack of interest in activities that they once enjoyed are also signs that children might be involved in things that are unhealthy.

However, if you would like your children to have access to the wide array of opportunities the web offers, consider taking some simple safety precautions that will also help your children learn to take responsibility for their actions. In this Tech Talk column, I'll give you some basic guidelines, an example of safety rules you might want to have your children adopt, and resources for further exploration of this topic. Let's start with some simple steps you can take to help keep your kids safe when they're out on the information superhighway.

PLACE YOUR INTERNET-CONNECTED COMPUTER IN A HIGH-TRAFFIC AREA

If the internet-connected computer is in the family room or other busy area, children will be less likely to engage in inappropriate activities. Avoid having a computer with an internet connection in a child's bedroom; this might be a better place for a computer with educational software, applications software, and games, but no internet connection.

continued on page 96

Dr. Sheryl Burgstahler is the director of the DO-IT (Disabilities, Opportunities, Internetworking, and Technology) program. DO-IT is funded by the US Deptartment of Education, the state of Washington and many other organizations. DO-IT serves to empower young people with disabilities as they transition to college and careers through the use of computers, assistive technology and the Internet. "Tech Talk" is designed to address practical ways of integrating technology into educational, work and home environments. Dr. Burgstahler will also answer readers' questions through this column. Please send correspondence to: Dr. Burgstahler, University of Washington, Box 354842 Seattle, WA 98195; fax: (206) 221-4171; e-mail:sherylb@u.washington.edu.

NEVER PAY FULL PRICE AGAIN!!

EP PREFERRED BUYER CLUB OFFER!

EP PREFERRED BUYER CLUB!!

A Charter Membership in the EP Preferred Buyer Club includes the following special benefits:

- * A personalized EP Membership Card
- * 10% Discount on all books in the EP Library
- * 10% Discount on all videos in the EP Library
- * 20% Discount on all EP Monographs and Special Reports
- * $7.50 Discount on annual subscription to EP Magazine or renewal during term
- * One free ticket to the World Congress Exposition on Disabilities
- * Gift Certificate for FREE SHIPPING on next order
- * Only $24.95 per year

Take advantage of this dynamic offer now!
You can sign up any one of the following ways:
CALL 800-535-1910 or Visit
www.eparent.com & www.eplibrary.com

YES!! I want to join the EP Preferred Buyer Club so that I won't have to pay full price again !

Mail to: Exceptional Parent Dept: Membership P O Box 1807 Englewood Cliffs, NJ 07632-1207
Or Order on-line: www.eplibrary.com/epreferredbuyerclub/ Fax (201-947-9376 Or call 800-535-1910

Name: ____________________

Address: ____________________

City: ____________________ **State:** __________ **Zip Code:** __________

Telephone: ____________________ **Email:** ____________________

I have enclosed my check payable to Exceptional Parent or charge to my:

☐ VISA ☐ Mastercard ☐ AMEX ☐ Discover

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ , **Exp. Date:** ___/___ **Signature:**

Resources

There are many web sites that provide information about Internet safety and guidelines to promote child safety. Here are a few places to start:

Child Safety on the Information Highway
National Center for Missing and Exploited Children
www.safekids.com/child_safety.htm

FTC's Tips for Parents
Federal Trade Commission
www.ftc.gov/bcp/conline/edcams/kidzprivacy/adults.htm

How to Keep Kids Safe in Chat Rooms
www.chatdanger.com

Internet Safety: A Note to Parents, Guardians, and Teachers
Internet Safety Committee
Worldkids.net/school/safety/internet/guidance.html

The Librarian's Guide to Cyberspace for Parents and Kids
American Library Association
www.ala.org/parentspage/greatsites/safety.html

A Parent's Guide to Internet Safety
Federal Bureau of Investigation
www.fbi.gov/publications/pguide/pguide.html

Safety on the Internet
University of Oklahoma Police Department
www.ou.edu/oupd/inetmenu.htm

A Safety Net for the Internet: A Parent's Guide
New York Public Library
www.nypl.org/branch/safety.html

Teen Safety on the Information Highway
www.missingkids.com

Tips for Safer Surfing
Safesurf
www.safesurf.com/lifeguard.htm

continued from page 94

COMMUNICATE

Talk to your children about both the benefits and dangers of the internet. Describe scenarios in which a child could be exposed to inappropriate resources or communications. These conversations should be periodic and along the same lines as those about where it is safe for them to ride their bicycles and what to do if a friend wants to play with his dad's gun. Be clear about what activities your children are allowed to engage in, what types of internet resources are not appropriate for them, and what they are to do if they encounter materials that they feel uncomfortable with or that they know would not be acceptable to you. Consider allowing young children to use only web sites that you have previewed. Talk about what they should do if a friend exposes them to internet use they know is wrong. Be sure your children know never to arrange a face-to-face meeting with someone they "meet" on the internet without your permission. If you approve of a meeting between your child and a person met on the internet, make sure that the meeting is in a public place and that you accompany your child.

Agree on how much time they can spend on the net and during what times of the day. Teach them about "netiquette" – how to communicate in a polite manner, avoiding personal attacks and inappropriate language and topics. Tell them not to give out identifying information such as their last name, home address, phone number or school name in a chat room, on an email discussion list, or in a message to an individual that you and your children do not both know and trust. Tell your children to never respond to messages that are harassing, threatening, of a sexual nature, obscene or that just make them feel uncomfortable.

SHOW GENUINE INTEREST, PARTICIPATE

Keep communication open. Regularly observe and ask your children what activities they are participating in on the net. Show interest in what they are doing. Have your children get online with you, then do things together. Ask them to show you what they like to do. Join your children when they are in chat areas and other communication forums. Search for resources together. You may be surprised at how much fun the two of you can have.

TALK ABOUT NEGATIVE EXPERIENCES ON THE NET

Tell your kids about times when you have received unwanted email or encountered objectionable material on the internet and about how you handled the incidents. Encourage your children to tell you if they find themselves in these situations, too. If they do, use the opportunity to remind them that not all people on the internet (or anywhere else) share the values of your family, then talk about how your children might avoid such incidents in the future, and why it is important that they not inadvertently engage in conversations by responding to an inappropriate message. Consider sending an email with a copy of the inappropriate message to your Internet Service Provider (ISP) and to the National Center for Missing and Exploited Children's Cyber Tipline at www.missingkids.com/cybertip. If you respond calmly, objectively, and take this proactive step, your children are more likely to confide in you the next time they have a problem and will learn how to handle similar situations in the future.

CONSIDER USING TECHNOLOGICAL TOOLS TO CONTROL ACCESS

Some ISPs and other online services allow parents to limit their children's access to certain types of resources, such as web sites, chat rooms, and bulletin boards that contain sexual content, violence, or prejudice; that promote the use of drugs or alcohol; that suggest activities that are dangerous or illegal; or that contain other materials considered inappropriate for children. Some services even have special areas that are just for kids. Your internet browser—the program you use to navigate—may also include features that can help you limit your children's access to web sites that are rated inappropriate for children. Separate software programs can also be purchased to facilitate safe surfing. Most of these programs can be configured by parents to filter out specific types of web sites. You can find a list of filtering programs and other resources for parents at the Tools for Families Web pages at www.getnetwise.org/tools/. None of these tools are fail-proof and your children may be able to work around them. They do not eliminate the need for consistent adult supervision.

REVIEW YOUR BROWSER HISTORY

Most internet browsers automatically save a list of the web pages recently viewed. From time to time, consider checking this history list to learn what sites your children have been visiting.

REVIEW YOUR CREDIT CARD BILLS

Check for charges that your children might have made while on the net.

DO NOT POST PHOTOGRAPHS AND NAMES OF YOUR CHILDREN ON FAMILY WEB SITES

It's tempting to brag about your kids by posting their pictures and names on your personal or family web site, but revealing personal information like this can compromise the safety of your children.

CONSIDER HAVING YOUR CHILDREN USE FICTITIOUS NAMES WHEN THEY COMMUNICATE IN PUBLIC FORUMS ON THE NET

Your children can get free web-based email addresses that do not include their names or suggest their genders. These email addresses could be used when they communicate in chat rooms or on discussion lists or bulletin boards. Also consider having them share an email address with you, especially if they are young children.

Tell your children that "friends" online may not be who they seem. It is

continued on page 99

southpaw enterprises®
DAYTON, OHIO U.S.A.

Providing Hundreds of Sensory Integration and Development Product Solutions!

Therapists, educators, parents and physicians acknowledge Southpaw as the industry leader in providing high-quality, state-of-the-art and safe Sensory Integration and Developmental products. Our products are made to the strictest standards of quality. We also strive to make our products fun while providing you with the innovative and safe solutions you require for great therapy.

Phone toll free:
1-800-228-1698

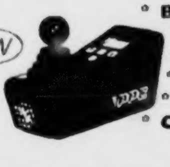
Or contact us from our website:
www.southpawenterprises.com

Call for our FREE full line product catalog!

2001 Southpaw Products Catalog

Southpaw Enterprises
P.O. Box 1047
Dayton, OH 45401-1047

Circle #79 or visit www.eparent.com/adinfo


The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW

- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made in U.S.A.

Circle #46 or visit www.eparent.com/adinfo

BARRIER FREE LIFTS®

"Portable" PC-2™

Easily Carried to Other Lifting Areas.

Tonya™
Multi-Purpose
Lift With
Electric Patient
Positoner,
Specifically Sized
for Children.

Call Us
TOLL FREE
NATIONWIDE:
800-582-8732

9230 PRINCE WILLIAM ST.
MANASSAS, VA 20110
WEB SITE: http://bfl-inc.com

Our Lifts Are:

- Premier Ceiling And Floor Model Lifts.
- Ergonomic for Safe Lifting.
- Used Independently or with Assistance.
- Battery Operated.
- Designed to Fit Your Needs! Bathrooms, Bedrooms, Work & School.
- Designed with a Variety of Slings Which Offer a Safe Secure Fit.

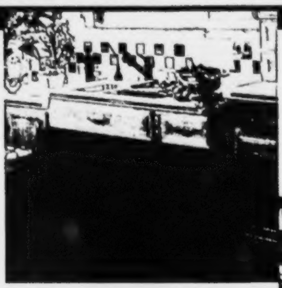
"Helping You Achieve Greater Mobility!"

Circle #24 or visit www.eparent.com/adinfo

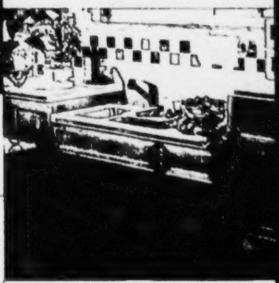
When designing an accessible kitchen, why not take the right Approach™?

Now you can finally get the accessibility you need without sacrificing style or functionality. The Approach™ line brings you convenient height-adjustment for your sink, cooktop and cabinets. Push-button height adjustment and ample knee space mean accessibility with no compromises—you get the design flexibility that lets you take the very best approach to your kitchen.

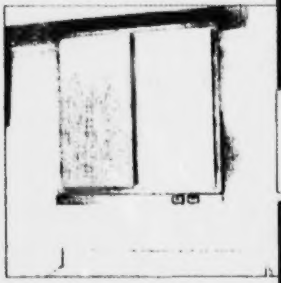
AD○AS



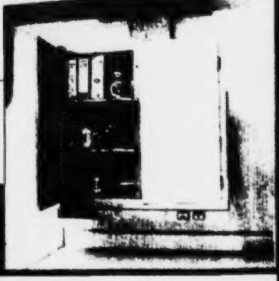
ΔV Approach™
for the sink



Reprinted with permission of GE Appliances



ΔV Approach™
for the cabinet



Approach™ for the Kitchen from AD•AS.
To request a catalog, call 800.208.2020 or visit www.ad-as.com

Circle #18 or visit www.eparent.com/adinfo

continued from page 97

easy for people to misrepresent their gender, age, and other personal information. That "14-year-old cheerleader" they are corresponding with might in reality be a 65-year-old pedophile. Regularly remind them that some things posted online are not true. They should be particularly suspicious about offers for products that seem "too good to be true"—they probably are.

ESTABLISH FAMILY RULES FOR INTERNET USE

The specific rules you establish should depend upon the ages of your children, the level of control you wish to exert, and your family values. Consider adopting a set of rules similar to My Rules for Online Safety, published by the National Center for Missing and Exploited Children (www.safekids.com/child_safety.htm). Tailor them with your children and post them near the internet-connected computer in your home. For example:

- I will not give out personal information such as my address, telephone number, parents' work address and telephone number or the name and location of my school without my parents' permission.
- I will tell my parents right away if I come across any information that makes me feel uncomfortable.
- I will never agree to get together with someone I "meet" online without first checking with my parents. If my parents agree to the meeting, I will be sure that it is in a public place and bring my mother or father along.
- I will never send a person my picture or anything else without first checking with my parents.
- I will not respond to any messages that are mean or in any way make me feel uncomfortable. It is not my fault if I get a message like that. If I do, I will tell my parents right away so that they can contact the online service.
- I will talk with my parents so that we can set up rules for going online. We will decide upon the time of day and length of time I can be online and appropriate areas for me to visit. I will not access other areas or break these rules without their permission.

KEEP PERSPECTIVE

Taking steps to keep our children safe from individuals who do not have their best interests in mind provides an opportunity to share with our children facts about the real world and to reinforce the values we hold dear in our own families. **EP**

Healthcare, Education...& Love.
50 years of CARE

- Nationally recognized facility
- Sub-acute/residential/rehabilitation
- Serving children with medically complex, special education, rehabilitation and /or behavioral needs
- Multi-disciplinary team of professionals
- Latest assistive technology services available
- Transitional planning to home, school, & community
- Medicaid/Medicare/private insurance/ educational funding
- Birth to age 22

For more information or a free telephone assessment, call now:

800-584-9294

CHILDREN'S CARE HOSPITAL & SCHOOL
For Children with Special Needs and Their Families
Sioux Falls, South Dakota www.cchs.org

Circle #30 or visit www.eparent.com/adinfo

TWICE-EXCEPTIONAL:

Learning Disabled and Gifted

It's September and our children are heading back to school (whew!). I thought it appropriate in this back-to-school issue of EP to reflect on research that addresses a narrow but fascinating topic: children who are twice-exceptional, meaning that they have abilities in the gifted range as well as some significant learning challenges, and what parents and educators can do to help them.

Most school children can identify at least one famous person who had, or has, a disability (or two) but went on to achieve great things (e.g. Helen Keller, Stephen Hawking, Ludwig van Beethoven and Stevie Wonder). If you read EP's July, 2002 Research Reflections you know that Jim Eisenreich went on to play major league baseball despite his Tourette syndrome. Yet the combination of a learning disability and giftedness is not something we expect to find, and so it is often missed.

Many of us are old enough to remember learning the three R's: Reading, Writing and 'Rithmetic. Today's children often don't recognize the names of these skills, as they are now called "language arts," "writer's workshop," "core skills," "math" or, worse yet, "new math." Despite these new titles, about 7 percent of children are reported to have a disability, known as a "specific learning disability," in one of the three R's. This qualifies both the children and their parents for the title exceptional.

Children with remarkable abilities in these and other areas are also called "gifted," and denoted professionally as exceptional. Oddly enough, federal legislation that provides funding to children with exceptionalities does not include children with special talents or gifts, yet these children—and their parents—are also exceptional.

I was I think in 5th or 6th grade when I was given an IQ test, and they found my IQ as eligible for the gifted and talented program. Then they gave me a test they used for placement in the program. They told me I didn't make it but not to feel bad, because learning disabled [persons] usually score about 15 percent lower than normal people, so I probably would have made it if I had not been learning disabled. [From: Reis, Neu, & McGuire, 1997, p. 468]

Who is learning disabled and/or gifted?

The U.S. Department of Education reported that in 1994 more than four percent of school children in the U.S. (approximately two million children) received services for learning disabilities over one school year (http://www.kidsource.com).

The National Association for Gifted Children (NAGC) currently reports that five percent of the student population in the U.S. (approximately three million children) are gifted (http://www.nagc.org).

What is a learning disability?

According to the 1997 IDEA Regulations: "Specific learning disability is defined as…a disorder in one or more of the basic psychological processes involved in understanding or using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or do mathematical calculations, including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia." Of course there are additional criteria and alternative definitions, but these are beyond our scope here.

What is giftedness?

NAGC defines a gifted person as "someone who shows, or has the potential for showing, an exceptional level of performance in one or more areas of expression. The term giftedness provides a general reference to this spectrum of abilities without being specific or dependent on a single measure or index."

M. Elizabeth Nielsen and her colleagues are researchers focusing on children who are twice-exceptional. Their Twice-

Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, where she has been a researcher for 20 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of mental retardation, dual diagnosis and the transition to adulthood. Dr. Blacher has developed **Research Reflections** as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to **Research Reflections** and any suggestions you might have. Send e-mail to: jan.blacher@ucr.edu.

Exceptional Child Projects take place in the southwestern United States (Neilsen, 2002). Through their outreach and advocacy they have found that 3.5 percent of children with LD could also be identified as gifted.

Identifying children who are twice-exceptional

It is likely that either type of exceptionality (learning disabled or gifted) could mask the identification of the other. "These students have disabilities that conceal their gifts, and gifts that camouflage their disabilities" (McCoach et al., 2001, p. 405). Often special educators, along with teachers in general education, are quick to highlight deficits and concerns while overlooking unusual talents and assets. There is much professional support for the idea that all children— not just those who are "typical"— should be screened for giftedness (special gifts and talents).

D. Betsy McCoach and her colleagues at the University of Connecticut are working on developing "best practices" for the identification of gifted students with learning disabilities. They argue that learning disabilities can exist in children at all ability levels. Yet most school psychologists and practitioners would agree that screening all school children for hidden learning disabilities is not feasible. Thus, learning disabilities are not usually identified until the child begins to underachieve, and this unfortunately, may be too late. G. Reid Lyon, Chief of the Child Development and Behavior Branch of the National Institute of Child Health and Human Development at the NIH has noted that approximately 74 percent of students identified as LD after age nine continue to have reading difficulties during their school years. One goal for researchers then, is to more clearly identify characteristics of children, at any age and ability level, who have a learning disability.

In children with superior intelligence, identification of learning disabilities may come even later, if at all. Their giftedness can mask a bona fide learning disability. For example, if the disability is in reading, the child might be able to keep

continued on page 102

Anderson School

Building A Tradition of Service for Over 78 Years

Anderson School provides the highest quality programs possible for children (ages 5-21) and adults with autism and other developmental disabilities. Anderson School is an educational residential community committed to an ongoing and fully integrated support network for their families and guardians. As an organization, Anderson School constantly strives to provide an enriched and positive climate filled with educational, cultural and recreational activities designed to foster continuous growth, independence and social interaction.

Located near historic Hyde Park (approximately 95 miles from midtown Manhattan) on a scenic 100 acre wooded estate overlooking the Hudson River, Anderson School serves all of New York State and welcomes out of state applications.

Now Accepting Referrals

- Residential and day students welcome
- Students accepted throughout the year

Call Kate Haas, Director of Admissions (845) 889-4034 Ext. 534
4885 Route 9, Box 367, Staatsburg, New York 12580-0367
www.andersonschool.org E-mail: katehaas@andersonschool.org

Circle #19 or visit www.eparent.com/adinfo

continued from page 101

up well in the early grades because of superior compensatory abilities (e.g. outstanding verbal, reasoning or problem-solving skills). In the later grades, reading content becomes more difficult and abstract, and the child who is gifted may falter, earning average or even below-average grades.

A 2002 article in Exceptionality provides data related to this point. M. Elizabeth Nielsen reports child subtest scores on an intelligence test (WISC-R) and an achievement test (Woodcock Johnson Cognitive Abilities Test Battery-Revised) for three groups of children: those with LD only, those with giftedness only and those with both types of exceptionality. The gifted/LD children had a high IQ profile strongly resembling the gifted group and a low academic achievement profile, like the LD group. One worry is that teachers and parents may misidentify a lower-achieving gifted child as "unmotivated" or "inattentive" or "mismatched with the school," and miss the very real learning difficulties.

Case: Juan

Contributed by Dr. Sally M. Reis, University of Connecticut

Juan, a college student majoring in physics, experienced many difficulties in both his academic and personal life. Juan was labeled twice-exceptional, as he had experienced many problems in school due to his remarkably high abilities in one area paired with a learning disability in another area. Though his verbal IQ is over 140, he experienced problems in school at a very early age and was identified as having a learning disability in third grade. His learning disability involved both dyslexia and information processing disorders, which caused him to experience multiple learning problems in early elementary education.

Juan was subsequently placed in a full-time, self-contained special education classroom for students with disabilities in grades three through six. Other students in this class had been identified as having severe developmental disabilities, emotional or behavioral disorders or specific learning disabilities. During his years in this class, Juan became severely depressed and recalled, "This time in my life was degrading. I was very resentful of it. I don't really remember that part of my life that well. I've blocked it out. I knew I was different from the other kids."

Juan was retained in fifth grade while in the self-contained special education class, and remembers that he became a disciplinary problem at that time. He has terrible memories of his experiences. He explains, "They used to send us out to recess with the mainstream kids. I remember being sort of alone and being made fun of. They called me retarded."

Juan's parents explained that they had put their faith in the school personnel who had identified the learning disability and recommended this special education approach. When his parents understood the ramifications of these difficult school experiences, they sought professional counseling for Juan and placed him in a private school with small classes that provided a great deal of individual attention. Juan began to learn how to compensate for his learning problems and gained enough reading proficiency to read independently. However, spelling, reading and writing still remain problematic for him.

Other negative experiences influenced Juan's education. Despite his high aptitude, he was never provided any opportunity to develop his talents. Almost all of the time he spent in school was related to improving his reading and writing skills. Yet, these are still weak because of his learning disabilities. With the right types of support and the acquisition of compensation strategies needed to directly address his learning disability, he became successful.

Although currently involved in a university learning disabilities program, it is questionable whether Juan will finish college, as he continues to face academic challenges due to his learning problems. Juan carries a great deal of anger about what happened to him in school, particularly his elementary school years. He believes these experiences impeded his educational performance both at that time and later in his educational life. He continues in therapy and has the full support of his parents.

The risks of overlooking either exceptionality

Sharon Dole, in an article that appeared in the Roeper Review in 2000, has noted the heightened risk placed on children with LDs who are gifted. She lists the following social-emotional characteristics of such children that increase their vulnerability: poor self-concept, poor self-efficacy, hypersensitivity, emotional ability and high levels of frustration, anxiety and self-criticism. Researchers Susan Baum and Steven Owen studied three groups of 4th to 6th graders: students who were of high ability, average ability and high ability/learning disabled. The single largest factor that distinguished the high ability/LD group from the other two groups was a sense of inefficacy in school. While these high ability/LD children had tremendous creative potential, they also had disruptive behaviors and low levels of academic success. These two qualities place them at academic and behavioral risk and on a potential trajectory that could lead to school failure. This is a big price to pay for an overlooked learning disability.

What is a protective factor?

Resiliency is a popular theme these days. It refers to protective factors that buffer an individual's response to stressful life events. Psychologist Norman Garmezy has noted three categories of protective factors, all of which are relevant to gifted/LD children: personality factors (e.g. self-esteem, coping strategies), family cohesion and lack of disharmony and external support systems.

While gifted children with LD may be at risk because of their unusual combination

BEST COPY AVAILABLE

of gifts and disability, there is some disagreement as to whether giftedness increases the vulnerability of these children or strengthens their resiliency. One study described seven gifted children. All had unusual "cognitive appraisal" coping strategies, which required abstract thinking and intelligence, two indicators of resilience. In dealing with stressful situations, these children used problem-focused strategies (changing one's behavior to adjust to the environment) and emotion-focused strategies (changing one's interpretation of a situation). Other studies of protective factors have found benefits from early identification of a learning disability, intensive intervention during school years, ongoing support and counseling. The #1 protective factor in the lives of children who are twice-exceptional is ongoing parental understanding and support. Lest you think you have to leap tall buildings in a single bound, read on.

What can twice-exceptional parents do?

- Be involved in your child's school program.
- Identify attributes of giftedness.
- Identify behavior disruptions, learning struggles, or poor academic success in the face of high ability.
- Be aware of a mismatch between your child and his or her school placement.
- Provide emotional support and professional counseling as needed.
- Provide opportunities for involvement in extracurricular activities that will help develop self-esteem.
- Learn about the options available to address your child's giftedness as well as his or her learning disability.

Children who are twice-exceptional will have ongoing needs, demands and pressures as they move through important life transitions. It's easy for exceptional parents to get bogged down in working out the details of an IEP at each age and stage. But parents and teachers also need to be mindful of the exceptional skills the child brings to the table, and work twice as hard at developing those. **EP**

A list of studies on which this Research Reflections is based may be obtained by emailing requests to: epedit@aol.com.

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel**. Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

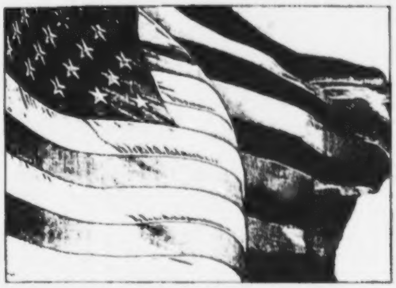
We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #45 or visit www.eparent.com/adinfo



LEGISLATIVE UPDATE

Washington Politicos Focus on IDEA Reauthorization

Special education is one of Washington's hottest topics right now, as the Individuals with Disabilities Education Act (IDEA) is up for reauthorization this year. This will affect the education of every child with disabilities in the United States.

The U.S. House of Representatives has been examining special education issues through the Subcommittee on Education Reform. In addition, President Bush formed a Commission on Excellence in Special Education to study special education issues at the federal, state and local levels and submit a report on their findings. The following are some issues receiving a lot of attention.

Full federal funding: This year, only 17 percent of the total cost of IDEA implementation was covered by the federal government. When IDEA was originally enacted, Congress pledged to pay 40 percent; this means that a significant increase in funding is needed to reach the level of federal support originally pledged.

President Bush's FY2003 budget calls for a $1 billion increase to IDEA, Part B funding, providing a total of $8.5 billion in grants to states. The budget resolution passed by the House of Representatives this spring includes the increase for next year as well as a 12 percent increase every year after that for the next nine years. The Senate is expected to act this fall. The goal is to reach full federal funding within a decade.

Early intervention: Many feel that the focus of IDEA should shift from simply accommodating those with diagnosed disabilities to preventing and intervening. As the Commission's report put it, "The model guiding education focuses on waiting for a

PATHFINDER VILLAGE
Specializing in Down Syndrome

Pathfinder Village is a warm, friendly community in the rolling hills of Central New York. Here children and adults who have Down syndrome realize success as they work in the community, go to school, and take part in recreation & social programs.

Pathfinder Village offers:
- 10 nurturing family homes
- a dedicated & caring staff
- year-long school with teen vocational program
- on-site nursing staff
- outreach services at the Kennedy • Willis Center on Down Syndrome
- a history in human services dating to 1922

As our residents grow in independence, they build lasting friendships, become partners in the world, and take in all that life has to offer.

PATHFINDER VILLAGE
3 Chenango Road
Edmeston, NY 13335-2314

Call 607-965-8377 or visit www.pathfindervillage.org

Circle #71 or visit www.eparent.com/adinfo

MIDWEST MOBILITY & DESIGN INC.
ACCESSIBLE TRANSPORTATION

DROP FLOOR MINIVANS
SPORT PICKUPS
4" x 6" DROP FLOORS
RAISED ROOFS & DOORWAYS

- Rental Vans
- In Stock Units
- New & Used
- Ship Anywhere
- Financing
- Trade-ins

WWW.MIDWESTMOBILITY.COM

1-800-809-3738
NATIONWIDE

1-847-923-9892
CHICAGOLAND AREA

Since 1972
An All-Star Distributor of Braun Mobility Products

★★★★★
5 Star Dealership

Circle #66 or visit www.eparent.com/adinfo

child to fail, not on early intervention to prevent failure." That is, instead of waiting for problems to present themselves, more effort should be made to provide help to children early on, when preventive measures may still give them a chance to catch up to their peers.

Overidentification of minority students: Studies have shown that disproportionate numbers of minority students are identified as having disabilities. While there is a documented link between poverty and disability, this factor alone cannot begin to account for the overrepresentation of minorities in special education. IDEA '97 requires states to gather racial data and to monitor identification levels, but the problem still exists and needs to be corrected.

Too much paperwork: President Bush has said that he wishes to reduce the amount of paperwork involved in special education, and to start focusing more on results than on procedures. While documentation is important and serves many useful purposes, many parents can attest to the fact that some of the paperwork currently required seems unnecessary or even irrelevant. What really matters is whether or not children are learning and succeeding in school; the methods used to help them do this are only of secondary importance.

Higher standards of accountability: Along with a change of focus towards "progress" instead of "process" comes a need for tools to measure achievement. The No Child Left Behind Act, signed into law this past February, requires all states to establish a statewide accountability system to measure "adequate yearly progress" in all students, including students with disabilities. This reinforces the IDEA '97 requirement that students with disabilities must have access to the general curriculum and must be included in state-wide assessments.

Training and retention of educators: Qualified special education teachers are increasingly difficult to attract, and general education teachers often need more information than they receive about how to address the needs of special education students in their classrooms. Educators are often eager for more support in the area of special education; the question is how to provide it. It is difficult to know how best to recruit and retain qualified professionals, but most people agree that this is key to providing students with the level of education necessary for them to succeed.

For more information on IDEA reauthorization, visit http://edworkforce.house.gov/issues/107th/education/idea/idea.htm.

To submit comments or suggestions to the Subcommittee on Education Reform, visit http://edworkforce.house.gov/issues/107th/education/idea/ideacomments/ideaform.htm.

To read the Commission's report, visit http://www.ed.gov/inits/commissionsboards/whspecialeducation/index.html.

JUDGE ROTENBERG CENTER

A Special Education School for Children and Young Adults

- Positive-only programming track serving 43% of students
- Day program opening in Fall of 2002
- Serving children and adults with autism, behavior/psychiatric problems and other disabilities
- Highly consistent behavior modification with widest range of treatment procedures available
- Minimal use of psychotropic medication
- Near zero rejection/expulsion policy
- Transition planning and vocational training
- Employment opportunities available

240 Turnpike Street, Canton, MA 02021
(781) 828-2202 Fax (781) 828-2804 www.judgerc.org

Circle #55 or visit www.eparent.com/adinfo

HMS Enables Active Learning

HMS School for Children with Cerebral Palsy serves children, ages 2-21, who have multiple disabilities resulting from cerebral palsy or traumatic brain injury. Skilled, compassionate staff and consultants provide individualized inter-disciplinary programs that enable each child to flourish and learn.

Day & Residential Programs • Special Education
Physical & Occupational Therapies • Speech/Language Therapy
Music Therapy • Nursing & Nutrition Services • Medical Support
Therapeutic Recreation

State-of-the-Art Assistive Technology:
Augmentative/Alternative Communication
Computer Access
Environmental Control
Powered Mobility

For more information contact
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy
– FOUNDED IN 1882 –
4400 Baltimore Ave., Philadelphia, PA 19104
215-222-2566 • Fax: 215-222-1889
www.hmsschool.org
E-Mail: admin@hmsschool.org

Member: NAPSEC • Pennsylvania's Alliance of Approved Private Schools

Circle #50 or visit www.eparent.com/adinfo

Getting information from EP advertisers is MUCH FASTER ONLINE!

It's as easy as a click of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers

CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in Exceptional Parent.
How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.

Be sure to tell them you saw their ad in Exceptional Parent!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
17	ABILITIES EXPO	79
26	ADAPTIVEMALL.COM	66
18	AD-AS LLC	98
19	ANDERSON SCHOOL	101
20	ANNANDALE VILLAGE	8
21	ANNE CARLSEN SCHOOL	117
23	BANCROFT NEUROHEALTH	85
24	BARRIER FREE LIFTS	98
25	BENEDICTINE SCHOOL	67
27	BERKSHIRE MEADOWS	30
28	BODYPOINT DESIGNS, INC	115
29	CAMPHILL SPECIAL SCHOOL	66
30	CHILDREN'S CARE HOSPITAL	99
31	CHILEDA INSTITUTE	38
32	COLUMBIA MEDICAL	87
33	CONNETQUOT WEST	88
34	CONVAID	15
35	COTTING SCHOOL	88
36	CROTCHED MOUNTAIN REHAB	84
37	CRYSTAL SPRINGS SCHOOL	38
38	CYBERONICS, INC	22-24
	CYCLETOTE CORP	93
39	DURALINE MEDICAL PRODUCTS	28
40	DYNAVOX SYSTEMS LLC	71
41	EDEN FOODS, INC	77
200	EP LIBRARY BOOK CLUB	95
200	EP LIBRARY PAGES	118-119
52	EP NEWBORN SCREENING DVD	86
199	EP SUBSCRIPTION CARD	17-18
51	EP TELECONFERENCE	73
42	EQUIPMENT SHOP	61
43	EVERGREEN CENTER	28
44	FREEDOM DESIGN	31
45	FREEDOM MOTORS USA	103
46	GLOBAL POWER SYSTEMS INC	97
47	H.D.I.S.	82
48	HARD MANUFACTURING	16
22	HEARTSPRING	83
49	HERTZ SUPPLY CO., INC.	91
50	HMS SCHOOL	105
	HOUSE AD	106
53	INNISFREE	34
54	INNOVATIVE PRODUCTS	35
92	INTERACTIVE METRONOME	70
55	JUDGE ROTENBERG EDUC. CTR	105
56	KENNEDY KRIEGER	21
57	KIMBERLY CLARK CORP	53
58	LAWYERS, INC	51
59	LIBERTY MOTOR COMPANY INC	3
60	LITIGATORS, INC	63
61	MANSEF	54
62	MARTHA LLOYD COMMUNITY SERV	60
63	MATHENY SCHOOL & HOSPITAL	92
64	MELMARK	12-13
65	METROPOLITAN LIFE INSURANCE	59
66	MIDWEST MOBILITY AND DESIGN	104
67	NAPSEC	61
68	NEW ENGLAND CNTR FOR CHILDREN	C2
	NEW ENGLAND VILLAGE	60
69	NOVARTIS NUTRITION	C3
70	OCEAN HYPERBARIC CENTER	113
71	PATHFINDER VILLAGE	104
72	PFIZER, INC	5
73	PRECISION FOODS	55
74	REAL DESIGN	29
75	RED BARN ENTERPRISES	93
76	REPLIGEN	57
77	SIGMA TAU	1-2
78	SNUG SEAT INC	39
79	SOUTHPAW ENTERPRISES, INC	97
93	STEPPING STONE RANCH	123
80	ST. VINCENT'S SPECIAL NEEDS	81
81	STEWART HOME SCHOOL	89
82	SURE HANDS INTERNATIONAL	67
83	THE BABY JOGGER COMPANY	34
84	THE CENTER FOR DISCOVERY	7
85	ULTRAFLEX SYSTEMS, INC	61
86	VAIL PRODUCTS	C4
87	VERIZON	9
88	VIEWPOINT MOBILITY LLC	54
89	WENZELITE MEDICAL SUPPLY	89
90	WOODBURY PRODUCTS	35
91	WORLD CONGRESS	44-47

SUBSCRIPTIONS
EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged.
The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75

MICROFILM: Microfilms of all issues are available from University Microfilms,
300 North Zeeb Road, Ann Arbor, MI 48106

EP

has the
nformation an
“Exceptional
Parent”
like you
needs

EP
Exceptional
Parent

Subscribe

on our

website:

ww.eparent.com

and save

$5.00

For telephone

orders

call:

877-372-7368

To start your subscription to EP today, fill out the card near the front of this magazine or log on to

www.eparent.com

EXCEPTIONAL PARENT Free product & service information order card* **SEPTEMBER 2002**

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______________________________

Address ______________________________

City ____________________ State ______ Zip ________

Phone ____________________ Fax ______________

E-mail: ______________________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or
young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children
or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No

If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist
^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist
^{10}☐ Other (please indicate) ______________________

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No

If Yes, are you a: ^{13}☐ Other (please indicate) ______________________

E. Do you buy or influence the purchase of products or services
for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No

If yes, please explain ______________________
____

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

***CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: February 28th, 2003**

RSEP2

EXCEPTIONAL PARENT Free product & service information order card* **SEPTEMBER 2002**

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______________________________

Address ______________________________

City ____________________ State ______ Zip ________

Phone ____________________ Fax ______________

E-mail: ______________________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or
young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children
or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No

If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist
^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist
^{10}☐ Other (please indicate) ______________________

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No

If Yes, are you a: ^{13}☐ Other (please indicate) ______________________

E. Do you buy or influence the purchase of products or services
for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No

If yes, please explain ______________________
____

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

***CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: February 28th, 2003**

RSEP2

To start your subscription to EP today, fill out the card near the front of this magazine or log on to

www.eparent.com

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

1084

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer lif for themselves and for their children.

Exceptional Parent's MISSION IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

Senate Bill for Disabled Children

Families of children with severe disabilities will soon be eligible for Medicaid benefits, pending Congressional approval of bill # S-321.

Approved by the Senate Finance Committee on July 11, 2002, the bill would allow families currently ineligible for the program because of high income levels to participate. About 200,000 children would benefit from this measure.

Families with annual incomes up to 250% of the poverty level, or $45,000 for a family of four, would be eligible. Currently, children under six are given access to these benefits only if their family's income is up to 133% of the poverty level, and children 6-18 have access only at 100% of the poverty level.

Sen. Charles Grassley (R-Iowa), the bill's sponsor, said the bill aims to prevent families from spending down their incomes or quitting their jobs to qualify their children for Medicaid.

National Disability Mentoring Day

National Disability Mentoring Day: Career Development for the 21st Century, will be commemorated on Wednesday, October 16, 2002.

NDMD's purpose is to draw attention to the importance of encouraging young people with disabilities to obtain job skills. Students and job seekers with disabilities, with the help of NDMD and mentors in the community, can learn and obtain careers.

Along with the American Association of People with Disabilities (AAPD), local communities can organize activities with volunteers at public and private places of employment.

If you are interested in participating, or coordinating activities in your community, please visit http://www.aapd-dc.org/mentor.html.

Definition of Mental Retardation

"Mental Retardation is not something you have, like blue eyes, nor is it something you are, like short or thin. It is a particular state of functioning..."(AAMR, 2002).

The American Association on Mental Retardation has recently released its tenth edition of "Mental Retardation: Definition, Classification, and Systems of Support." This edition incorporates new features and expands others to create a multidimensional system for diagnosing, classifying and planning supports that will improve the quality of life for people with mental retardation.

The AAMR will be holding two 2-day training sessions on their new definition in September 2002 in New Orleans, and October 2002 in Washington, DC.

For more information, please visit http://www.AAMR.org

BabySpa

For parents searching for baby care products without harsh ingreidients, BabySpa's Natural Touch products provide a solution. BabySpa designs its products to promote wellness and bonding between parents and their babies. It offers a variety of infant massage oils, shampoos, soaps and lotions, all made from natural ingredients such as aloe vera, lavender, cucumber, and jojoba oil, among others.

In additoion to cleansing products, BabySpa offers soothing CD's, cuddly textiles, and creative gift sets, all of which can be found in specialty shops, natural food stores and pharmacies.

BabySpa donates a portion of its profits to treat babies and children infected with HIV/AIDS.

For more information, or to order online, visit http://www.BabySpa.com.

National Council on Disability

Five nominees to the National Council on Disability were confirmed by the U.S. Senate on July 26, 2002. The NCD is an independent federal agency that makes recommendations to the President and Congress on disability policy.

The nominees are:

- Lex Frieden of Houston, TX, as chairperson. Mr. Frieden is senior vice president at the Institute for Rehabilitation and Research. He is also a professor of physical medicine and rehabilitation at Baylor College of Medicine.
- Young Woo Knag, Ph.D. of Munster, IN. Dr. Kang is an author and the founding president of Education and Rehabilitation Exchange Foundation International.
- Kathleen Martinez of Oakland, CA. Ms. Martinez is deputy director of the World Institute on Disability, which is dedicated to promoting independence and societal inclusion of people with disabilities.
- Carol Hughes Novak of Tampa, FL. Ms. Novak has a child with severe cerebral palsy, and was a member of the Bush-Cheney 2000 Disability Advisory Coalition.
- Patricia Pound of Austin, TX. Ms. Pound is the executive director of the Texas Governor's Committees on People with Disabilities. She is the founding president of the Coalition of Texans with Disabilities and a current member of the National Association of Governor's Committees on People with Disabilities.

For more information, contact Mark Quigley at 202-272-2004.

Straight From Her Heart

Victoria Guillot knows what it's like to be scared. This creative and caring 10-year-old has written a book about her feelings and fears of having diabetes.

Straight From Her Heart, Victoria's homemade booklet allows the reader to share in the thoughts of a child with an illness. Victoria wants to reach out to other children, to let them know they are not alone.

To order your copy, send a check or money order for $12.95 to:

Straight From Her Heart
122 Desoto Road
Plaucheville, LA 71362

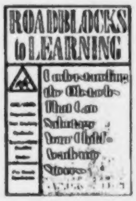
or send email to:
straigtfromherheart@yahoo.com

BEST COPY AVAILABLE

For Further Reading...

by Megan Henninger

Looking for more information on the education opportunities that exist for your child? These titles offer a glimpse of those available to help you! Access these and other titles by contacting the EP Library online (http://www.eplibrary.com), by fax (201-947-9376) or by calling (800) 535-1910.

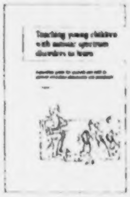


Roadblocks to Learning: Understanding the Obstacles that can Sabotage Your Child's Academic Success
By Lawrence J. Greene
EP Library Code: TW9011ED Price: $16.95

This general resource for parents aims to explain and define counterproductive behaviors and learning disorders that block a child's academic progress. The book lists common symptoms of each difficulty, defines important terminology and suggests testing protocol and remediation strategies (when appropriate). Resources provided include a bibliography and 2 appendices.

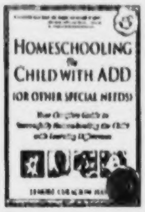
Wrightslaw: Special Education Law
By Peter W.D. Wright
& Pamela Darr Wright
EP Library Code: HP0037SE or HP0037SECD (with CD ROM)
Price: $29.95 or 39.95 w/CD-ROM

This sequel to *Wrightslaw: From Emotions to Advocacy* (see EP June 2002) is divided into five parts. Section 1 discusses law itself and provides an overview of special education law. Section 2 deals with the Individuals with Disabilities Education Act of 1997, providing the text of IDEA, an overview and a table that breaks down its regulations. Section 3 outlines the Rehabilitation Act of 1973 (Section 504), and Section 4 details the Family Educational Rights and Privacy Act. Section 5, entitled "Case Law," gives an overview of how to apply case law to advocacy.



Teaching Young Children with Autistic Spectrum Disorders to Learn: A Practical Guide for Parents and Staff in General Education Classrooms and Preschools
By Liz Hannah
EP Library Code: NA2099AT Price: $21.95

This book of activities provides tips to help develop early communication skills, prerequisite skills for early learning (such as sitting down, concentrating, etc), literacy skills, social interaction skills, imagination and flexible thought. Behavior support strategies are also covered, with the underlying reminder that difficult behavior is a reflection of difficulties children are experiencing. Also emphasized are the TEACCH method (Treatment and Education of Autistic and related Communication-handicapped Children) and structured teaching (showing the child exactly what the task is and what will happen when it is finished). References for further reading and additional resources conclude the book.



Homeschooling the Child with ADD (Or other Special Needs): Your Complete Guide to Successfully Homeschooling the Child with Learning Differences
By Lenore Colacion Hayes
EP Library Code: PR5691HS Price:$16.95

Hayes' writing covers the path many parents take when considering homeschooling as an alternative education option. It begins with diagnosis of the child, developing confidence to teach your child and removing your child from school. Then Hayes walks through the process of selecting learning materials, handling family and friends and where to go for homeschooling support. Each chapter concludes with a list of books, organizations, periodicals and/or web sites that can be used as resources.

Including Students with Severe and Multiple Disabilities in Typical Classrooms: Practical Strategies for Teachers, 2nd Ed.
By June E. Downing, PhD
(with invited contributors)
EP Library Code: PB5192ED Price: $39.95

This guide to inclusion provides the rationale for inclusion coupled with instruction ideas for the general education classroom. According to Downing, the first step lies in "determining individual abilities and how to best support students." Subsequent chapters develop this idea and apply it to preschool students, elementary students, middle school/junior high students and high school students. Four appendices at the back of the book outline systematic teaching resources, adaptive communication resources and videotapes on inclusion.

Nonverbal Learning Disabilities at School: Educating Students with NLD, Asperger Syndrome and Related Conditions
By Pamela B. Tanguay
EP Library Code: TF9416AS Price: $24.95

As a mother of a child with NLD, this author provides valuable resource. The book not only explains NLD, but also addresses environmental issues that will affect the child at school, suggests possible teaching strategies and discusses social and emotional functioning. Each chapter ends with a summary that outlines the basic points emphasized. Appendices that conclude the book provide a glossary of terms, annotated bibliography, internet resources and helpful organizations.

PART XIV

Oral Health for Adults with Disabilities

Dental treatment for adults

Paul Farsai, DMD, MPH, Joseph Calabrese, DMD

Approximately 50 million Americans have some type of disabling condition. "Special care dentistry" is a term commonly used for addressing the oral health needs of a person who is medically compromised or an individual with some type of mental, physical or developmental disability. This type of dental treatment may be provided in private practice, community health centers, group homes, long-term-care facilities, skilled nursing facilities or hospitals. It typically involves modifying the process of the dental examination and of the required dental treatment to accommodate the person's disability.

Special care dentistry may include consulting with the person's physician, coordinating dental treatment with other care providers, assisting a person with the aid of the family and direct support professionals (DSPs), adaptations to the treatment procedure, communicating through an interpreter and treatment planning with the person to mitigate future oral health problems.

Oral diseases for individuals with disabilities do not differ from those of individuals without disabilities. Various factors related to the disability, however—such as grasping a toothbrush or articulating the source of oral pain—make it more difficult to prevent and treat dental disease. Keep in mind that, as children and teenagers, adults with disabilities are likely to have had inadequate oral health care. Thus treatment may also differ, because the disease is typically addressed at a later stage, and must often be adapted to fit the needs of the individual's physical and cognitive impairments.

Adults with disabilities are subject to the same ailments and chronic diseases (eg, heart disease, lung disorders, arthritis, type II diabetes) as adults without disabilities—except that these conditions may manifest themselves 15 to 20 years sooner in people with disabilities. This means that a 30-year-old adult with mental retardation/development disabilities (MR/DD) may have a level of oral health similar to that of a 50-year-old person without disabilities.

Common changes seen as people with disabilities age

Certain oral conditions appear more often in persons with specific disabilities, partly because of the disability itself, but also because of behavior patterns that accompany the disability.

For example, in many people with MR/DD, the teeth erupt in an altered pattern, which may result from over-retained primary (baby) teeth or even the malformation of the teeth. If left untreated, delayed eruption patterns will lead to poor alignment and positioning (malocclusion) of teeth.

Broken teeth are commonly seen in individuals with disabilities; they may result from falls caused by poor ambulatory skills or seizure disorders.

continued on page 112

continued from page 111

Another cause might be the behavioral tendencies of repetitive body movements and fixation on certain tasks that are characteristic of people with autism. These tasks typically include chewing on hard, non-edible objects that tend to break teeth.

Dry mouth (xerostomia) is a common and often-overlooked oral health problem. Once considered an inevitable consequence of aging, it is now known that saliva production remains essentially unchanged in healthy elders. Yet the secretion of saliva may be indirectly dependent on individuals' systemic health as well as the number and type of medications that they are taking. Medications used to treat high blood pressure, heart disease, diabetes, allergies, depression and many other conditions have been found to cause dry mouth.

Medications used to treat high blood pressure, heart disease, diabetes, allergies, depression and many other conditions have been found to cause dry mouth.

Saliva maintains the oral environment by limiting bacteria, strengthening tooth enamel, lubricating tissues and enhancing taste sensation. Diminished salivary flow is associated with increased burning and soreness of the oral tissues, difficulty in chewing, swallowing and speaking, oral infections and overall mouth feel, all of which can adversely affect food selection and dietary compliance. Dry mouth can further contribute to the accumulation of food debris around teeth, which can lead to advanced stages of tooth decay, gum disease or even tooth loss.

Cavities or caries (tooth decay) are the result of bacteria breaking down the hard tooth structure. This process typically occurs when food debris and bacteria are not adequately removed from the teeth. A diet high in sugar and carbohydrates also increases the incidence of tooth decay.

Decayed roots (root caries) occur when gum recession and/or bone loss cause the exposure of the roots of teeth, leading to decay on the root surface of the tooth. The exposed root is more susceptible to root caries if oral hygiene is not adequate.

Gum disease (gingivitis) appears as red, inflamed and/or bleeding gum tissue. The inadequate removal of food and bacteria from the gum causes gingivitis. The appropriate removal of debris from the gum tissue can reverse the condition. If left attached to teeth for longer periods, bacteria can cause irreversible bone loss and other tissue abnormalities (periodontitis). In its more advanced stages, gingivitis leads to tooth mobility and even tooth loss.

Missing teeth (tooth loss) can be an upsetting ordeal to an individual, particularly if the missing teeth are not replaced. The three most common causes of tooth loss are advanced tooth decay, advanced periodontal disease, and trauma from falls or accidents. Many options are available today for persons seeking treatment to replace their missing teeth.

Tooth replacement (dental prosthesis) is done to fill the spaces left by missing teeth. Restored chewing ability and improved aesthetic value can play an important role in helping to improve a person's quality of life. Following a clinical examination, appropriate treatment options should be discussed by the dentist and the person, family member or DSP.

Bad breath (halitosis) is caused by a number of factors. It often results from upper respiratory conditions caused by excessive mucous buildup, infections or even poor digestion. However, halitosis can very easily originate in the oral cavity because of inadequate oral hygiene, large cavities or even advanced periodontitis.

Food pocketing (pouching) is a condition in which individuals who are unable to chew or swallow accumulate their food between their cheeks/lips and their gums. Pouching of food debris and medications not only results in significant dental and medical consequences but can also lead to malnutrition.

Regurgitation (rumination) is a characteristic seen in many individuals with mental disabilities. Individuals swallow their food and then regurgitate it with the stomach fluids and acids, leading to severe indigestion and malnutrition. In persons who have excessive drooling of saliva, dental professionals should also consider problems with pouching and regurgitation.

Appropriate dental care for adults with disabilities

Following a comprehensive clinical examination, the dentist will present treatment options to the person, family member or DSP.

The dental treatment plan should be formulated according to accepted den-

EC 1088

tal practice and take into consideration such basics as:

- Addressing the person's immediate pain or infection
- The person's mental status—the level of disability, understanding and communication, and psychological and social needs
- The effects of the current oral condition on the quality of life
- Physical impairments
- The person's capacity for self-care and care management

Oral hygiene

Brushing teeth should ideally take place in the morning, after each meal and before bedtime. Toothbrushes can be modified to enable people with physical and mental disabilities to brush their own teeth and decrease the incidence of pouching. Certain electric toothbrushes may improve compliance. Use of fluoride toothpaste or gel has been shown to maximize the effects of a good regimen for oral health promotion and disease prevention.

Flossing should be accomplished daily; however, it may be difficult for individuals with movement disorders and other disabilities to do so, and a second person may be needed. Flossing helps prevent the accumulation of food debris between the teeth that leads to various types of dental disease.

Mouthwashes or rinses are beneficial in managing gingivitis and periodontal disease under the direction and care of a dentist or a hygienist. Mouthwashes should be swished and spit out (never swallowed); persons who might swallow a rinse could benefit from its application with a toothbrush or cotton swab rather than rinsing. A prescription mouthwash with the active ingredient chlorhexidine is recommended, as it has been shown to have antibacterial qualities. This mouth rinse is also recommended as an adjunctive aid in managing gum disease. Rinses that contain fluoride have also been proven to be effective in preventing cavities.

Dietary counseling is necessary for long-term prevention of dental disease as well as weight management and overall health. This is especially significant in individuals with a compro-

continued on page 114

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

Coming Soon!

HYPERBARIC OXYGENATION FOR THE COMATOSE CHILD

There is some hope for the comatose child suffering from severe brain injuries, cerebral palsy, or anoxic encephalopathy. Children with Glasgow Coma scales from 3-5 present tremendous financial and emotional burdens, since these little ones may live for many years. When considering care of tracheotomy, gastric tube for feeding, physical therapy, occupational therapy, speech therapy, nursing care, recurrent hospitalizations, medications, vans, and modifications to the home, expenditures may represent multi-million dollars.

Intensive hyperbaric oxygenation is no miracle, but it provides some hope. In certain instances the child is able to communicate verbally, by computer or word board. Eighty percent have the G-tube removed and seventy percent have the tracheotomies closed. Frequently, bowels become normal and nutrition is re-established. Routine monthly medications are reduced and hospitalizations are markedly decreased. Although few children will return fully to society, substantial improvements will give them a better quality of life in addition to a ninety percent reduction in overall costs.

For more information on hyperbaric oxygenation therapy and life planning, call the Ocean Hyperbaric Neurologic Center at (800) 552-0255.

Hyperbaric Oxygenation for Cerebral Palsy and the Brain-Injured Child..

by R. A. Neubauer, M.D.

Dr. Neubauer's new book is a complete guide written for the professional as well as the caregiver of exceptional children. The book describes the latest information on hyperbaric oxygenation therapy including improved brain function as visualized through functional imaging. Clinical and scientific data along with references are included.

Call 1-800-552-0255 to order.

(800) 552-0255
• Call for free video & information

For more information, visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

Circle #70 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of hyperbaric oxygen therapy. For Editor-in-Chief statement see our Contents page.

continued from page 113

mised health status and individuals having difficulty chewing or swallowing.

Treatment goals

The first appropriate treatment goal is to improve or stabilize the oral condition of the person who has not received dental care recently. Stabilization of the oral condition keeps individuals who have not had routine care free of acute disease.

Most of the acute oral conditions that are commonly seen in adults who have physical, mental or developmental disabilities have been discussed above. However, a clinical examination may reveal other oral conditions that will need appropriate—even immediate—care. This is why the importance of a comprehensive clinical exam cannot be over-emphasized.

Medicare is the largest federally funded health care system in the United States, yet it does not include a specific dental component.

Once the acute disease is stabilized, the next step will be the restoration of the oral health and function. An appropriate maintenance schedule to oversee the person's reestablished oral health can then be designed.

Disease prevention and maintenance of the mouth

The first step in obtaining compliance with oral hygiene recommendations is to promote the person's involvement through education and demonstration tailored to the person's level of impairment. This maximizes acceptance of the oral condition and supports independence vis à vis oral health. If persons are unable to participate in the educational/instructional process, family members and DSPs are encouraged to assume this responsibility.

Educating family members and DSPs is also critical to ensure appropriate and regular supervision of daily oral hygiene. The person's oral care should be monitored daily and oral care assistance provided as needed.

Certain adaptive aids may improve the manual dexterity and physical manipulation of a toothbrush: large-sized toothbrush handles, for example, or making cuts on either end of a racquetball or tennis ball and sliding the handle of a toothbrush through the two cuts. Other useful and appropriate material used in the oral health care of an individual with disabilities may include electric toothbrushes, antimicrobial mouth rinses and oral lubricants that resolve oral discomfort associated with the gum tissues.

Barriers to treatment for adults with disabilities

Aside from the oral health care supports needed by many individuals with disabilities there are other significant barriers that prevent access to proper oral health care.

Insufficient numbers of dental health providers: One barrier includes the low number of dental health providers trained specifically to treat people with disabilities. Most dentists already treat adults with certain physical impairments and medical conditions. As health care improves and many once-acute and -advanced conditions become chronic or manageable, the number of persons with disabilities will continue to grow and to seek care from traditional private or community-based services. At the same time, the expected lifespan of individuals with disabilities continues to increase because of improvements in medical and social services.

Informed consent and treatment decisions: A major determining factor in providing any type of treatment for a person with a disability is the need for dental professionals to obtain informed consent for treatment. Most individuals with MR/DD have legal guardians whose consent is required before the proposed treatment can begin.

Inadequate financial coverage: Poor reimbursement for dental services is clearly a hinderance to properly addressing the dental needs of people with disabilities. Lack of adequate financial coverage may dictate certain compromises in dental treatment plans.

Medicare is the largest federally funded health care system in the United States, yet it does not include a specific dental component.

Medicaid can be a source of payment for dental services, but not all state Medicaid plans offer dental care coverage for adults; typically, coverage is limited and varies across states. Also, the majority of dentists in most states are not Medicaid providers, so the scope of dental services through Medicaid is even more limited.

Further complicating Medicaid coverage in many states are the eligibility restrictions for adults based on the level of disability. In other words, adults who may have a milder yet still significant level of disability may not be eligible for Medicaid.

Sometimes reimbursement, although at a lower level, is available for certain types of dental care through Medicaid Waiver Programs, grants through local and state dental societies/associations

Circle #36 or visit www.eparent.com/adinfo

or through the state Developmental Disabilities council. State dental societies are good sources of more information about available programs.

State-run agencies such as public health clinics and community health centers can also serve as resources for obtaining access to oral health care. Many individuals with disabilities have access to social workers, support coordinators or caseworkers who may be able to assist in obtaining full or partial funding for specific dental services.

Why Oral Health?

There is a significant relationship between general health and oral health. For example, oral health and nutrition are reciprocal. The condition of the teeth and supporting tissue has an effect on nutritional intake, quality of life and systemic health. At the same time, poor nutrition can weaken the teeth and supporting tissue. The oral cavity is often the site where signs and symptoms of many systemic diseases are first manifested. Oral health is much more than healthy teeth and gums; it is integral to both general health and the quality of life.

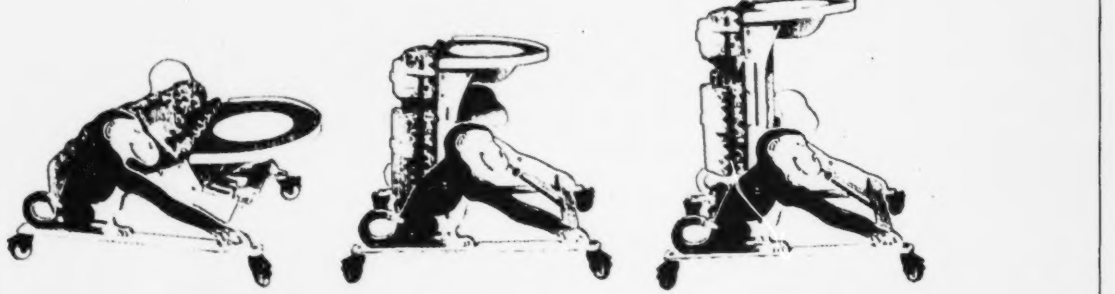
For a list of sources for additional information on oral health care for adults with disabilities, please email your request to epedit@aol.com, fax it to 201-489-0074, or mail to Adult Dentistry, Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. EP

The authors wish to thank Dr. Steve Perlman, Global Clinical Director of the Special Olympics Special Smiles program, for his review of this paper.

Paul Farsai, DMD, MPH is an Assistant Professor in the Department of General Dentistry, Boston University Goldman School of Dental Medicine, and is also in private practice in Lynn, MA.

Joseph Calabrese, DMD is an Assistant Professor in the Department of General Dentistry, Boston University Goldman School of Dental Medicine; Clinical Instructor in the Department of Oral Health Policy and Epidemiology, Harvard School of Dental Medicine; and the Director of Dental Medicine at Hebrew Rehabilitation Center for the Aged in Boston, MA. He also has a private practice.

Help your child rise to any occasion.



Like you, Jenx and Bodypoint Designs would never do anything to inhibit your child's ability to participate in the world. And that's precisely why we'd like to share another great feature of the unique positioning tools that Jenx has created: Adjustability.

With Jenx, you can raise or lower your child to accommodate just about any activity they're involved in. Each Jenx animal has a range of adjustments that promote positive therapeutic benefits, the most important being that your child can finally feel part of the group.

Being included does wonders to help your child rise to any occasion. And whether the group is on the floor or standing at the play table, Jenx helps make your child a part of it all. Just one more reason to make Jenx your first choice in positioning equipment.

JENX Distributed by BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Circle #28 or visit www.eparent.com/adinfo

NATIONAL

Ability Camp, Inc.
Center for Conductive Education and Hyperbaric Oxygen Therapy Providing separate and combined programs for children with C.P. For a free video call
1-800-442-6992
www.abilitycamp.com
Circle # 16
See our ad on page 123

CALIFORNIA

Blind Children's Learning Center
18542-B Vanderlip
Santa Ana, CA 92705
(714) 573-8888
Fax: (714) 573-4944

CONNECTICUT

St. Vincent's Special Needs Services
95 Merritt Blvd.
Trumbull, CT 06611
P: (203) 375-6400
F: (203) 380-1190
e-mail: feroleto.child.dev@snet.net
Providing education and therapeutic day programs for children, 0-21 with multiple medical/developmental needs.
Circle # 80
See our ad on page 81

GEORGIA

Annandale Village
3500 Annandale Lane
Suwanee, GA 30024
P: (770) 945-8381
F: (770) 945-8693
www.annandale.org
Full residential and day programs paid vocational training, job placement, recreational activities, case mgt., creative and performing arts, meals and counseling.
Circle # 20
See our ad on page 8

Cloister Creek Educational Center
P. O. Box 80310
Conyers, GA 30013
P: 770-483-0748
F: 770-918-8217
email: clcreek@bellsouth.net
www.cloistercreek.org
Stepping Stones Ranch
Conductive Education Center
4479 Robinson Rd.
Toccoa, Ga. 30577
P: 706-282-0862
e-mail rrshultz @aol

ILLINOIS

Brehm Preparatory School
1245 E. Grand Ave.
Carbondale, IL 62901
P: 618.457.0371
F: 618.529.1248
www.brehm.org
Boarding school for students with learning disabilities 6-12. Post-secondary program for students at the junior college level.

IOWA

Easter Seals Iowa
PO Box 4002
Des Moines, IA 50333
essia@netins.net
Serving individuals with disabilities. For CARF-accredited career training, call (515) 274-1529. For summer ACA-accredited camping, year-round respite, call (515) 289-1933.

KANSAS

Heartspring
8700 East 29th Street N.
Wichita, KS 67226
P: (800) 835-1043
Fax: (316) 634-0555
Our campus provides a positive, practical environment for multidisciplinary programs that include education, life skills, communication, and behavior management. We serve children ages 5-21 with multiple disabilities.
www.heartspring.org
Circle # 22
See our ad on page 83

KENTUCKY

Stewart Home School
4200 Lawrenceburg Road Dept. B
Frankfort, KY 40601
P: (502) 227-4821
F: (502) 227-3013
www.stewarthome.com
Circle # 81
See our ad on page 89

MARYLAND

Maryland Association of Nonpublic Special Education Facilities (MANSEF)
P.O. Box 6815
Baltimore, MD 21285
(410) 938-4413
Fax: (410) 938-5130
e-mail: mansef@aol.com
www.mansef.org
Circle # 61
See our ad on page 54

MASSACHUSETTS

Berkshire Hills Music Academy
48 Woodbridge St.
S. Hadley, MA 01075
(413)540-9720
Fax: (413)534-3875
info@berkshirehills.org
www.berkshirehills.org
A unique two-year post-secondary transition program for special learners with musical abilities.

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 021[illegible]6
P: (413) 528-2523
F: (413) 528-0293
School for people of all ages with severe developmental delay. They may be medically involved. We offer comprehensive and integrated medical residential and educational services. All therapeutic services are included.
www.berkshiremeadows.org
Circle # 27
See our ad on page 30

Cardinal Cushing Center
400 Washington Street
Hanover, MA 02339
(781) 829-1205
Fax: (781) 826-1559
e-mail: dfrazier@coletta.org
http://www.coletta.org
Our school provides day and residential services to students with developmental disabilities and other secondary conditions.

Cotting School
453 Concord Avenue
Lexington, MA 02421
P: (781) 862-7323
e-mail: jbrownsmith@cotting.org
www.cotting.org &
www.cottinghopehouse.org
A day school for students with physical, learning, medical and communication challenges.
Circle # 35
See our ad on page 88

Evergreen Center
345 Fortune Boulevard
Milford, MA 01757
P: (508) 478-2631
F: (508) 634-3251
www.evergreenctr.org
e-mail: services@evergreen.org
Circle # 43
See our ad on page 28

IDDI, Crystal Springs School
38 Narrows Road
Assonet, MA 02702
P: (800) 840-8087 ext. 375
F: (508) 644-2008
e-mail: Css372@aol.com
Circle # 37
See our ad on page 38

Judge Rotenberg Educational Center
240 Turnpike Street
Canton, MA 02021
P: (781) 828-2202
F: (7810 828-2804
e-mail: k.lachance@judgerc.org
www.judgerc.org
Circle # 55
See our ad on page 105

New England Center for Children
33 Turnpike Road
Southboro, MA 01772
P: (508) 481-1015
F: (508) 485-3421
www.necc.org
State of the art day/residential school and group homes for children with autism, PDD, developmental disabilities & behavior disorders, age 3-22. Curriculum covers communication, academics, social & life-skills, employment. Recipient of U.S. Dept. of Education's National Award for Model Professional Development.
Circle # 68
See our ad on page C2

New England Village, Inc.
664 School Street
Pembroke, MA 02359
P: (781) 293-5461, ext. 110
F: 781-294-8385
e-mail: jandracchio@newenglandvillage.org
www.newenglandvillage.org
See our ad on page 60

Riverbrook Residence, Inc.
4 Ice Glen Road, P.O. Box 478
Stockbridge, MA 01262
(413) 298-4926
Fax: (413) 298-5166
www.riverbrook.org
e-mail: riverbro@berkshire.net
Serving women with MR Opportunities for voc., social and creative growth. Shared living in integrated community setting 24 hr. supports.

NEW HAMPSHIRE

Crotched Mountain Rehabilitation Center
1 Verney Drive
Greenfield, NH 03047
P: (603) 547-3311
F: (603) 547-3232
Fully accredited by the NEASC and CARF, the Crotched Mountain Rehabilitation Center offers the very best of residential and day programs for children with complex special needs. Visit our Internet site at: http://www.cmf.org
Circle # 36
See our ad on page 84

NEW JERSEY

Bancroft NeuroHealth
Hopkins Lane, P.O. Box 20
Haddonfield, NJ 08033-0018
P: (800) 774-5516
www.bancroftneurohealth.org
Programs in NJ, DE, LA, ME & CA. Serving children and adults with Autism, developmental disabilities and brain injuries. Offering a full range of education, vocational, therapeutic, rehabilitation and residential programs, plus behavior intervention, day treatment and diagnostic outpatient services.
Circle # 23
See our ad on page 85

Davis Centers Inc.
98 Rt. 46 West
Budd Lake, NJ 07828
973-347-7662
Fax: 973-691-0611
www.thedaviscenter.com
E-mail: info@thedaviscenter.com
Offering AIT, Tomatis, BioAcoustics, Interactive Metronome, Fast ForWord, Read Spell Comprehend, The Listening Program, OT, hearing, speech and CAP testing

Matheny School and Hospital
P.O. Box 339, Main Street
Peapack, NJ 07977
P: (908) 234-0011
e-mail: info@matheny .org
www.matheny.org
Res., outpt., ed (3-21), respite for d.d.
Circle # 63
See our ad on page 92

NEW YORK

Anderson School
4885 Route 9
Staatsburg, NY 12580
Tel: 845-889-4034
Fax: 845-889-3104
www.andersonschool.org
Residential/Day school serving children ages 5-21 who have been diagnosed with autism or other developmental disabilities dedicated to providing the highest quality programs possible.

Pathfinder Village for Down Syndrome
3 Chenango Road
Edmeston, NY 13335
(607) 965-8377
www.pathfindervillage.org
e-mail: info@pathfindervillage.org
Circle # 71
See our ad on page 104

The Center for Discovery (SDTC)
Box 8400 Benmosche Road
Harris, NY 12742
(845) 794-1400
Fax: (845) 794-1474
www.sdtcdiscovery.org
www.discoveryifi.org
Offering people with significant disabilities and their families, innovative and comprehensive educational, clinical, social and residential experiences designed to enrich their lives through personal accomplishments and increased independence.
Circle # 84
See our ad on page 7

NORTH DAKOTA

Anne Carlsen Center for Children
301 7th Avenue NW
Jamestown, ND 58401
(800) 568-5175
Phone/Fax (701) 252-3850
www.annecenter.org
Educational, therapeutic and residential services through age 21. Our evaluation team travels to your home and school setting.
Circle # 21
See our ad on page 117

OHIO

St. Rita School for the Deaf
1720 Glendale Milford Road
Cincinnati, OH 45215
P: (513) 771-7600
F: (513) 326-8264
www.srsdeaf.org
Educating deaf and hearing impaired children birth to 21 yrs. from across the country and world since 1915. Day and residential programs available. Philosophy based on comprehensive communication.

OREGON

UPWARD BOUND CAMP FOR PERSONS WITH SPECIAL NEEDS
P.O. Box C
Stayton, OR 97383
(503) 897-2447
Fax: (503) 897-4116
e-mail: ubc@open.org
www.upwardboundcamp.org
ACA accredited Christian program serving persons 12 yrs-80+ yrs w/primary label of MR/DD skilled staff, fun & friends year round camp & respite.

PENNSYLVANIA

CAMPHILL SPECIAL SCHOOL
1784 Fairview Road
Glenmoore, PA 19343
(610) 469-9236
Fax: (610) 469-9758
www.beaverrun.org
e-mail: bvrrn@aol.com
Circle # 29
See our ad on page 66

DR. GERTRUDE A. BARBER CENTER
136 East Avenue
Erie, PA 16507
P: (814) 453-7661
F: (814) 454-2771
e-mail: gabcmain@drbarbercenter.org
Educational/residential/vocational/employment facility serving children and adults with disabilities with state of the art programming.

ELWYN
111 Elwyn Road
Elwyn, PA 19063
P: 610.891.2546
F: 610.891.2903
www.elwyn.org
150 years of educating children with special needs; day and residential options from birth to age 21, early intervention, integrated preschool, elem., secondary and alternative Ed. with clinical supports, physical, recreational and adjunctive therapies; continuum services available after schooling years.

HMS SCHOOL FOR CHILDREN WITH CEREBRAL PALSY
4400 Baltimore Avenue
Philadelphia, PA 19104
P: (215) 222-2566
F: (215) 222-1889
Circle # 50
See our ad on page 105

MARTHA LLOYD COMMUNITY SERVICES
190 West Main St.
Troy, PA 16947
570-297-2185
FAX: 570-297-1019
information@marthlloyd.org
www.marthalloyd.org
Circle # 62
See our ad on page 60

MELMARK, INC.
2600 Wayland Road
Berwyn, PA 19312
P: 1-888-MELMARK
F: 610-353-4956
www.melmark.org
Serves children and adults with MR, ranging from mild to severe, neurological disorders, Autism, PDD, Asperger's, and acquired brain injury. A 24 hour learning model - day and residential programming, nursing care, OT/PT, adaptive therapies; aquatics, hippotherapy, recreation, & multi-sensory programs.
Circle # 64
See our ad on page 12-13

SOUTH DAKOTA

CHILDREN'S CARE HOSPITAL & SCHOOL FOR CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES
2501 West 26th Street
Sioux Falls, SD 57105-2498
(605) 782-2300 or (800) 584-9294
Serving children birth to 22 with medically complex, special education, rehabilitation and/or behavioral needs. Sub-acute, residential, accredited rehabilitation programs.
http://www.cchs.org
Circle # 30
See our ad on page 99

TEXAS

TEXAS NEUROREHAB CENTER
1106 West Dittmar Rd.
Austin, Texas 78745
(800)252-5151 or (512)444-4835
Fax (512) 462-6636
www.psychiatricsolutions.com
Providing brain injury/neurobehavioral treatment for children & adolescents with complex medical, physical and/or behavioral issues.

VERMONT

AUSTINE SCHOOL FOR THE DEAF AND HARD OF HEARING
60 Austine Drive
Brattleboro, VT 05301
P: 802-258-9500
F: 802-254-3921
www.austine.pvt.k12.vt.us

VIRGINIA

CUMBERLAND HOSPITAL FOR CHILDREN AND ADOLESCENTS
9407 Cumberland Road
New Kent, VA 23124
(800) 368-3472
www.brownschools.com/cumberland
Cumberland Hospital provides comprehensive medical, behavioral, and educational services to youth ages 2-22.

INNISFREE
5505 Walnut Level Road
Crozet, VA 22932
P: (434) 823-5400
F: (434) 823-5027
e-mail: innisfreevillage@prodigy.net
www.avenue.org/innisfree
Circle # 53
See our ad on page 34

WASHINGTON DC

THE NATIONAL ASSOCIATION OF PRIVATE SPECIAL EDUCATION CENTERS (NAPSEC)
1522 K Street, NW
Suite 1032
Washington, DC 20005
P: 202-408-3338
F: 202-408-3340
napsec@aol.com
www.napsec.com
Circle # 67
See our ad on page 61

WISCONSIN

CHILEDA INSTITUTE
1020 Mississippi Street
LaCrosse, WI 54601
P: (608) 782-6480
F: (608) 782-6481
www.chileda.org
Circle # 31
See our ad on page 38

Changing
Lives
Forever

The Anne Carlsen Center for Children offers a 60-year tradition of residential, therapeutic and educational services on one campus. Our individualized services include care for children and young adults coping with cerebral palsy; orthopedic, vision and hearing impairments; autism, pervasive and other developmental disorders; and many other medical challenges. Our multidisciplinary team can reach out to you by conducting evaluations in your child's home and school setting.

Anne Carlsen
Center for Children
Changing lives forever

Jamestown, North Dakota
Call 1-800-568-5175 or visit our
web site at: annecenter.org

Circle #21 or visit www.eparent.com/adinfo

1093

WWW.EPLIBRARY.COM

EP Exceptional Parent LIBRARY

THE SPECIAL NEEDS BOOKSTORE

AUTISM

THINKING IN PICTURES
My Life With Autism
TEMPLE GRANDIN WITH
A FOREWORD BY OLIVER SACKS
The author is a gifted animal scientist who has designed one third of all the livestock-handling facilities in the US. She is also autistic, a woman who thinks, feels, and experiences the world in ways that are incomprehensible to the rest of us. In this unprecedented book, the author delivers a report form the country of autism. Writing from the dual perspectives of a scientist and an autistic person, we learn how the country is experienced by its inhabitants and how she managed to breach its boundaries to function in the outside world. What emerges is a document that sheds light on the riddle of our common identity.
RH118AT $12.00

NEW

AUTISM IN THE EARLY YEARS
Resource Materials for Teachers: A Practical Guide
VAL CUMINE, JULIA LEACH AND GILL STEVENSON
Designed to provide parents and professionals with an insight into the nature and educational implications of autism, particularly as it presents in very young children. Also aims to equip Early Years practitioners and parents with knowledge of a range of intervention strategies to promote learning, social development, communication and appropriate behavior.
TF5992AT $25.95

NEW

CREATING A "WIN-WIN IEP" FOR STUDENTS WITH AUTISM
A How-To Manual for Parents and Educators
BETH FOUSE, PH.D.
This Second Edition, has been written to provide parents and families of students with autism necessary information and skills to meet the challenges of the IEP process. This book takes readers through the child-centered educational process from the stages of initial diagnosis to implementation ad of student's individualized educational programs. Practical suggestions are provided based on federal and state legislative requirements, case law, and the many years of experience the author has in working with the process as a teacher, special education administrator, regional special education consultant and university instructor.
FH7287SE $29.95

A WORK IN PROGRESS
Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism
RON LEAF AND JOHN MCEACHIN
A superb collection of ideas and programs for building skills as well as strategies for dealing with challenging behaviors. It is a comprehensive guide presented in user-friendly language so parents and professionals can easily understand and use this valuable resource.
DR6600AT $42.95

IEP

PLANNING FOR SUCCESS
The College Application Process for Students With Learning Disabilities
The college admission process can be a confusing and overwhelming experience for students with learning disabilities and their families. This comprehensive video enables you to see the college application process from the very beginning. It shows early planning, college visits, the essays, and how to choose the best school for you.
LD201LD $79.99

THE COMPLETE IEP GUIDE
How to Advocate for Your Special ED Child
LAWRENCE M. SEIGEL
A comprehensive step by step guide through the entire IEP process that provides encouragement to the reader as it takes a complicated process and makes it easier to understand. Provides instructions, suggestions, strategies, resources, forms and much more.
NL001SE $24.95

HOW TO WRITE AN IEP
JOHN ARENA
Parents, teachers, administrators and others involved in IEP preparation and implementation will profit from this brief, easy-to-use, handbook. This text will serve as an invaluable reference for making sure all factors of consequence are given the consideration they require.
NEW THIRD EDITION
AT1649SE $19.95

EDUCATION

COOPERATIVE LEARNING AND STRATEGIES FOR INCLUSION
Celebrating Diversity In the Classroom
JO ANNE W. PUTNAM
This guide shows educators how to make group learning strategies work in their classrooms. There are chapters written by a distinguished array of professionals who reveal the real educational benefit of a cooperative learning environment.
PB167ED $26.95

NEW

EFFECTIVE COMMUNICATION
Collaborative Practices For Educators Strategies for Effective Communication
PATTY LEE, ED.D.
This new revised edition includes 60 strategies and 180 practice activities designed to improve communication and collaboration skills. The activities may be used in any order allowing you and your colleagues to focus on one specific area or work in several areas simultaneously! Covers six (6) critical areas: Developing Expectations; Preparing Ahead; Understanding Perspectives; Listening; Asking Questions and Speaking Clearly.
PP5261ED $19.95

DYSLEXIA

DYSLEXIA, FLUENCY, AND THE BRAIN
MARYANNE WOLF
Consider the time it takes for the brain to process written language. What impact does the brain's processing time have on reading development? What are the relationships among processing time, reading fluency, and dyslexia? Can time and fluency related problems be changed? How should intervention be designed to address the issue. This monumental resource presents evidence indicating that many dyslexic children have a second core deficit in rate of processing linguistic differences in multiple areas. This book has been constructed to bring several levels of evidence and types of research to bear on these questions.
YP2602DY $30.00

NEW

LEARNING ABOUT LEARNING DISABILITIES
Second Edition
BERNICE WONG
Targeted for the advanced student and professional this text covers a wide range of topics to ensure a comprehensive and balanced coverage of important areas in learning disabilities. Included are conceptual issues, basic research in memory processes and social aspects of learning disabilities intervention research in academic areas and nonacademic areas, issues in service delivery and a life span perspective.
ACP5321LD $59.95

GRIEVING

WHAT ON EARTH DO YOU DO WHEN SOMEONE DIES
TREVOR ROMAIN
A down to earth explanation for children about death. It offers many ways for children to cope with and understand what is happening.
FS400DE $7.95

GUIDING YOUR CHILD THROUGH GRIEF
MARY ANN ENSWILER, MA, MRS, AND JAMES P. ENSWILER, MA, M.ED
This caring and compassionate guide offers expert advice during the difficult days to help a child grieve the death of a parent or sibling. This book helps readers understand the many secret ways children grieve and offers more insight information, and advice that can help a child heal.
BD0257GR $13.95

REMEMBERING WITH LOVE
Messages of Hope for the First Year of Grieving and Beyond
ELIZABETH LEVANG, PHD.
AND SHEROKEE ILSE
An affirming gift for those grieving the loss of a loved one, offering compassion, comfort and guidance with over three hundred short pieces written by those who have been there.
FP040DE $11.95

MENTAL RETARDATION

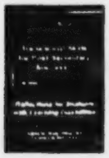
MENTAL RETARDATION IN THE 21ST CENTURY
SPONSORED BY THE ARC OF THE UNITED STATES, EDITED BY: MICHAEL L. WEHMEYER AND JAMES R. PATTON
An interesting and provocative prediction of where technology and society are headed with respect to the treatment of mental retardation in the coming century. Seven Sections covering Family Issues; Education Issues; Employment and Residential Issues; Psychology Issues; Medicine and Health Issues; Life Span Issues and Policy Issues.
PE181MR $ 44.00

EP LIBRARY • (800) 535-1910 • EPLIBRARY@AOL.COM

NEW

The Burden of Sympathy
How Families Cope with Mental Illness
David A. Karp
This book captures the essence of caring and caregiving for society today. It carefully discusses the emotional and social forces that are at play when caring for a mentally ill person.
OU3158MR **$25.00**

LEARNING DISABILITIES



NEW

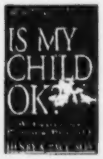
Transitional Skills for Post Secondary Schools
Reflections for Students with Learning Disabilities
Rick Lavoi and T. Citro
A thorough, extensive resource that will prove to be an invaluable guide for parents and students with learning disabilities. This book not only helps students make the transition from the protective environment of home to the university campus but offers a roadmap, for making that transition, and the college years that follow, a success.
LD7110LD **$24.99**

Einstein and Me: Talking About Learning Disabilities
A Video for Parents, Kids & Teachers
Jerome J. Schultz, Ph.D.
An upbeat, informative and optimistic video of kids talking openly and honestly, telling about how they found out about their learning disability; policies and people who make life difficult; people and programs that helped them cope, their strengths and talents.
LD100LD **$99.00**

GENERAL

Your Child Has a Disability

Your Child Has A Disability
Mark L. Batshaw, M.D.
When a child is diagnosed with a disability, parents can be overwhelmed by day to day physical and emotional demands. This comprehensive volume offers some welcome assistance with expert advice on a wide range of medical and educational issues.
PB160LD **$24.95**



Is My Child OK?
When Behavior Is A Problem, When It's Not, and When to Seek Help
Henry A. Paul, MD
Every parent has asked this question at one time or another. This wise and compassionate guide offers reassuring words for worried parents as well as concrete ways to spot problems between a normal stage of development…and a true problem. This one step reference book tells parents what is normal, what is not, and where to get help.
RH8878GN **$13.00**

Sleep Better
V. Mark Durand Ph. D.
This text begins with a discussion of sleep followed by a description of a range of sleep problems and includes a step by step interview that will help you identify the type of problems being encountered. Includes treatment options covering bedwetting, sleep walking, insomnia and much more.
PB166GN **$23.95**

NEW

Pathways to Learning in Rett Syndrome
Jackie Lewis and Debbie Wilson
Parents and Teachers of girls with Rett Syndrome will welcome this extraordinary book that offers accessible advice on the special education needs of these girls. It also assists teachers in developing a working knowledge of the syndrome and suggests particular strategies in planning a curriculum which may help overcome the specific difficulties within the diagnosis.
TT5333RS **$26.95**

FOR YOUNG PEOPLE

NEW

Never Sell Yourself Short
Stephanie Riggs
with photographs by Bill Youmans
Josh is a stereotypical teenage boy. He plays sports, spends time with his friends, and can't wait to drive. Josh is also short statured, and in this inspiring essay he talks about life in a world that is scaled for people much taller than he. His story is inspirational for everyone with obstacles to overcome in order to chase their dreams.
AW5630YP **$15.95**

NEW

Special People Special Ways
Arlene Maguire; Illustrated by Sheila Bailey
This book presents a positive image of persons with disabilities using a delightful rhyme and rich watercolor illustrations. It shares the message that even though each of us may have something different about us, we share many commonalties.
FH7651GN **$14.95**

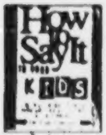
NEW

Taking Cystic Fibrosis to School
Cynthia S. Henry
with illustrations by Tom Dineen
This heartfelt children's story helps to explain for kids and their parents what cystic fibrosis is, how it is treated, and what activities children can participate in with others.
JJ3094YP **$11.95**

NEW

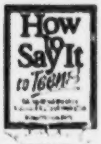
Allie Learns About Alzheimer's Disease
A Family Story About Love, Patience, and Acceptance
Kim Gosselin
with illustrations by Tom Dineen
This touching story about a girl and her relationship with her grandmother who suffers from Alzheimer's Disease is an excellent way for parents to introduce such difficult topics such as family healthcare to their children.
JB3159AZ **$14.95**

PARENTING



NEW

How to Say It to Your Kids
The Right Words to Solve Problems, Soothe Feelings, and Teach Values
Dr. Paul Coleman
This insightful and beautiful parenting manual is filled with a wealth of information that you can immediately use to transform your children's lives. It accurately predicts the traps many fall into and offers practical and sensible advice for dealing with many issues parents face when raising any child.
PH1773PA **$14.00**



NEW

How to Say It to Teens
Talking About the Most Important Topics of Their Lives
Richard Heyman, Ed.D.
If men are from Mars and women are from Venus, then teenagers are from an entirely different universe. Here you'll discover surprisingly easy ways to keep the lines of communication open throughout your child's turbulent adolescent years.
PH1883PA **$16.00**

The Don't Sweat Guide for Parents
Reduce Stress and Enjoy Your Kids More
Richard Carlson, PhD
This insightful guide provides suggestions for enjoying your children more while being less stressed and more present with them in every moment of their lives. Strategies that are discussed include admitting that you could use some help, learning to take a breather, keeping the job at the office, and many more.
TW7184PA **$10.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: **EP**, Dept. EP0902, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call **800•535•1910**

QTY.	ITEM#	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item
Foreign – $7.00 for 1 item; 75¢ for each additional item

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

These prices are subject to change without notice.

Name ______________________________

Address ______________________________

City ____________________ State ________ Zip ____________

Telephone ____________________ E-Mail ______________________

I have enclosed my check payable to Exceptional Parent or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover

Account Number: ____-____-____-____ Exp. Date ____/____

Signature ______ 1095 ______

Circle #200

new products

THER-A-SAUR

Ther-A-Saur "The Therapeutic Dinosaur" is a gel-filled, dinosaur-shaped hand exerciser. Designed for children three years of age and up, Ther-A-Saur provides assistance in fine motor skill development, stress relief, sensory stimulation and hot-and-cold therapy. This hand strengthener is available in three colors, each representing a resistance level. For example, soft resistance is availalbe in gold, medium resistance is green and hard resistance is blue. Ther-A-Saur is washable with antibacterial soap.

Ther-A-Saur Products Inc., P O Box 763, Hightstown, NJ 08520, 609-587-6302 voice/fax, E-mail: Dinotherapy@aol.com, Web Site: http://www.therasaur.com

RING SUPPORT WALKER

The Ring Support Walker is a height- and angle-adjustable, weight-bearing gait trainer with a zero to twenty-degree tilt-in-space feature. The Ring Support Walker comes with a contoured low back support, built-up hip positioning belt and casters with locking brakes.

Dragon Fly Toy Company Inc., 5725 South 5th Street, Pembina, ND 58271, 800-308-2208, 204-453-2320 Fax , E-mail: service@dragonflytoys.com, Web Site: http://www.dragonflytoys.com

DYNAWRITE

DynaWrite is a direct selection communicator appropriate for ambulatory and non-ambulatory individuals. This "type and talk" communication device offers a full-sized computer keyboard, shoulder strap and screen which can be viewed indoors and outdoors. Lightweight and compact, DynaWrite features VeriVox natural-sounding synthesized human speech in a choice of three voices: Sarah (adult female), Michael (adult male), and Jamie (child). DynaWrite also comes with built in environmental control unit capability, an integrated help menu and file management capabilities.

DYNAVOX Systems LLC, 2100 Wharton Street, Suite 400, Pittsburgh, PA 15203, 888-697-7332(voice), 412-381-5241 (fax), Web Site: http://www.dynavoxsys.com

SUNSUIT

The Sunsuit is an Ultra Violet protection alternative for children who have sunscreen allergies. This swimsuit also conceals G-tubes and protects scars from surgery. Made of nylon and lycra, Sunsuit is resistant to water, wind, stains and bacteria. The Sunsuit is lightweight, loose fitting and comes in vibrant colors and patterns.

JADL, Inc., 6 Bar Beach Rd., Port Washington, NY 11050, 800-227-4308 pin 88(voice), 516-767-9128 (fax), E-mail: joanne@uvpro.com, Web Site: http://www.uvpro.com

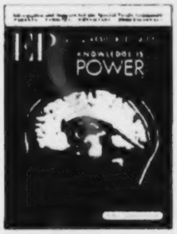
---

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.



EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/handling). To order, call 1-800-535-1910.

Circle #1

INTRODUCING

the Invacare® Top End® Terminator® Jr. for kids who are going places!

INVACARE
Yes, you can.

2001 Invacare Corporation. Invacare, Terminator, Top End and Yes, you can! are trademarks of Invacare Corporation.

Circle #2

freedom

what is your definition?

call us today!

1.800.661.9915
www.freedomconcepts.com

Circle #3

EYEGAZE COMMUNICATION SYSTEM

Lets your child communicate using only his eyes!

Eye controlled speech synthesis, environmental controls and PC/computer access

Now It's Portable!

800-393-4293 www.eyegaze.com
LC Technologies, Inc., Fairfax, Virginia

Circle #4

Diaper Doublers™

Diaper Doublers inserts that make cloth or disposable diapers more efficient, pulling moisture away from a child's tender skin.

- **Trim & Comfortable**
- **Overnight Protection**
- **Absorbency without Bulk**
- **Latex-Free for Sensitive Skin**

www.DiaperDoubler.com
1-800-335-4434
Toll-Free Phone Orders

"The Drier Way to Diaper"™

Circle #5

In CONTROL with COMFORT!

You'll feel the difference the minute you start using MYDESC. The product's ergonomic design allows you to easily swivel and tilt the desktop in all directions.

1-800-4 MYDESC
www.mydesc.com
Santa Clara, CA 95056

Circle #6

1097

MARKETPLACE

ACCESSIBLE TRAVEL

AFFORDABLE WHEELCHAIR VAN RENTALS
Orlando-Miami-Fort Lauderdale by Medical Travel Inc. Disney World Accessible Roll in Shower Villa's for RENT. Thinking of buying a Van—Price us Last. www.medicaltravel.org 1-800-778-7953

BEACH WHEELCHAIR

Affordable Independence in the Great Outdoors!

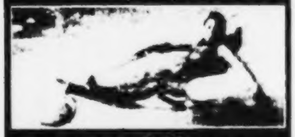
The Features Make All the Difference!

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure

BEACH SWIMMING POOL

TIRALO™
Floating Beach Chair

Call now: (360) 796-3197



www.oasisllc.com

CLOTHING

David's Collection

Fashionable & durable vinyl backed terry cloth **BIBS** made to order

Choice of pattern & style

Sm. $13.00
Md. $15.00
Lg. $17.00
[illegible] $3.50

NEW
Vinyl Backed Tie Bandanas
$6.50 [illegible]

CALL DAVID'S MOM
for more info — ordering
410-668-0068

Visit: www.DavidsCollection.com

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider. Resource information: www.medmarket.com e-mail: info@archhp.com

Ask about our Youth/Small Brief sample pack. Only $9.95

HDIS

FREE CATALOG

Call Today!
1-800-2MY-HOME®
(1-800-269-4663)

FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg, PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

EQUIPMENT DEALERS

American Discount Medical

Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

Special-Needs Collection

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

EXCERCISE VIDEOS

Let's Have Fun/ Let's Get Strong
Specifically designed for people with Dev. Disabilities. Easy to Follow Routines are FUN, Safe, & Effective. Low-impact aerobics. Improve Muscular strength. More Info call Laura at (631)864-9173 Website:WWW.healthyltd.com

MONITORING SYSTEM

Care Electronics Inc.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price. Call for FREE CATALOG

TOYS AND HOBBIES

TFH (USA) LTD
4537 Gibsonia Rd.
Gibsonia, PA 15044
800-467-6222
www.tfhusa.com
e-mail: info@tfhusa.com
Fun products for recreation and education of special needs children. Request a FREE catalog.

FUN & FITNESS!!™

WHIRLY WHEELS™
For Ages 3 to 7
& Up to 60 lbs.

DIZZY DISC™JR.
Ages 5 & Up
Up to 150 lbs.

Sensory And Gross Motor

Quantum Toys

www.quantumtoys.com

VAN CONVERSION DEALERS

MASSACHUSETTS

Motion Automotive Specialty
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions. Authorized Dealer. Accessible Van Rentals—Day, Week or Month.

1098

MARKETPLACE

SENSORY INTEGRATION

Sensory Integration Equipment

Providing custom-made weighted items. Sturdy, affordable, comfortable, non-clinical appearance.

Weight Vests
Weight Blankets

Angel Moon Creations
503-589-9552
www.angel-moon-creations.com
An OT Owned Company

SWITCHES

BUBBLES™ SWITCHES — for those who have difficulty using ordinary switches. Touch-sensitive, or it can be set so the hand only needs to pass near the switch! Convenient dome shape.

MINIMAL MOTION™ SPLINT SWITCH KITS — touch-sensitive switch pads to mount directly on hand splints.

EQUAL ACCESS COMPUTER TECHNOLOGY, INC. 978-466-9191
222 Grant Way, Lancaster, MA 01523
Email: eact@world.std.com

SWINGS

Portable Swing Stand

Therapy Swings

Safe, strong comforting & affordable for all your swinging and spinning needs

For more information contact
Take-A-Swing LLC
602-451-5544 • www.takeaswing.com

UNIQUE GIFTS

It's always the right time to appreciate those educators and healthcare professionals who work with our kids! At **www.4medspeak.com** you will find unique gifts for speech pathologists, special ed teachers, therapists, home caregivers, pediatricians, etc.

MEDICALLY SPEAKING
www.4medspeak.com

TO ADVERTISE IN MARKETPLACE CONTACT: **Barbara Nastro**

TEL: (908) 534-6366 • FAX: (908) 534-6941

Conductive Ed. Works At Stepping Stones Ranch

Stay in our western style building, located in the mountains of Georgia. Experience how Conductive Ed. can make a difference in the life of your child and family. We offer Parent/child training that will last a life time.
Offering year round 5 days 6 hrs a week sessions.

Limited space call 706-282-0862

www.childrenshopecenter.com

Circle #93 or visit www.eparent.com/adinfo

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:

1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

Send us your Adapted Halloween Costumes Ideas!

EP is looking for submissions for our annual Halloween Costume column.
Please send your photos with costume instructions to:

Exceptional Parent
Attn: Halloween Costumes
65 East Route 4, River Edge, NJ 07661

Send us your child's photo!

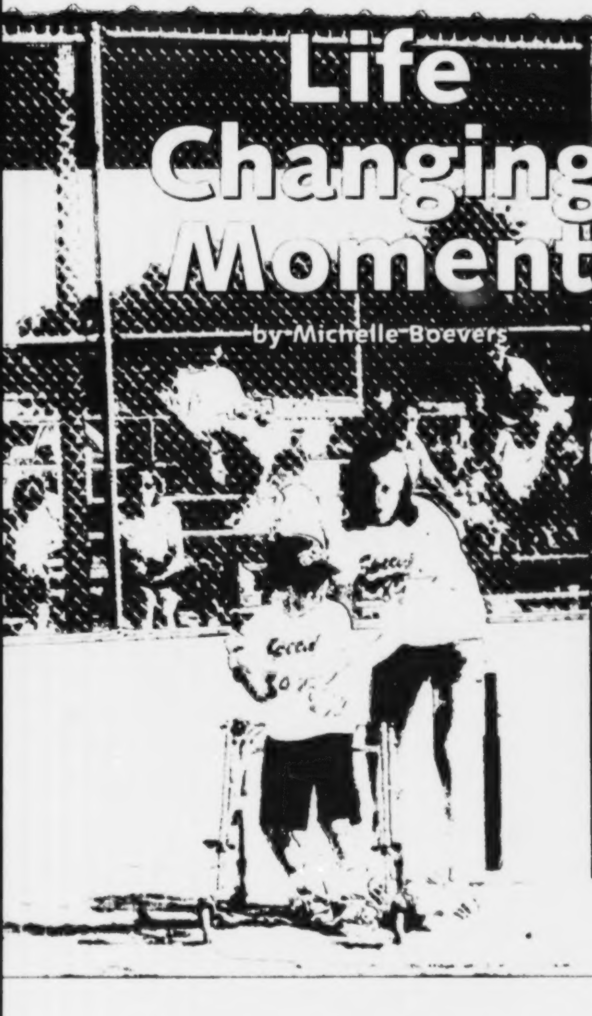
EP is always looking for submissions for our monthly *Familiar Faces* column.

It may just end up on our cover!

Send to: EP, 65 East Route 4, River Edge, NJ 07661

Life Changing Moment

by Michelle Boevers



People are different. If not by looks, then by their personalities. People judge. That's a fact. I judged other people until my brother Max came into my life. That's why he has changed my life. He has taught me about the importance of diversity.

The first time I held my brother in my arms, I thought to myself, "I've got so much to teach this little brother of mine." I soon found, however, that he would be the teacher. For example, my brother has taught me about loving people for who they really are, no matter if they have a disability or not. My brother has cerebral palsy, which is a condition involving the brain's sense of touch and balance. He uses a walker to help him walk. Even though he has CP, he can still run, jump, laugh and play like anyone else. To me and my family, he is normal. He also plays on a baseball team called the Special 89ers. He loves running around the bases as the crowd cheers him on. I just love watching the mile-wide smile on his face as he slides across home plate to score a run. He has been my teacher, showing me that anything is possible; for instance, just because someone cannot walk does not mean that they cannot score home runs! He has taught me to love him for his heart because he tries so hard.

Max has also taught me about diversity. Before he came along, I lived in a perfect little world; there were no trips to doctors in St. Louis or Salt Lake City. There was just my mother, my father and me. Max was this little kid dropped into a family of athletic stars, and of course I thought he would never fit in or that he would be the black sheep of the family. He fooled me though! Even though he puts tremendous effort into everything he does, he still does everything that we do. Ultimately, he has taught me that even though you may look different from others, it is what is inside that counts.

I used to judge people by the clothes that they wore. But since knowing Max, I can honestly say I don't do that anymore. Now I judge people by their hearts. This is important not only for people you know, but also for people you don't know. Every time I think about someone, I think about how Max would handle the situation. He does not judge.

Good things come in small packages. That is my brother Max. Even though he is younger than I am, he has taught me more than anyone else has. I love and admire him for that. Not only is he my brother, but he is my best friend, role model and teacher. EP

MOM'S TURN

Lisa Boevers, mother of Michelle and Max, writes: A mother always worries about family dynamics. When one of your children has special needs, it puts a whole new twist on the family structure. Many times our daughter has had to take a back seat to the needs of our son. I often worry about how this will affect her. When I read this essay, which Michelle wrote for her 9th grade English class, it warmed my heart. She wrote a loving tribute to her brother, but also showed the positive that can come from a special situation.

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number and e-mail address! ***Now on the Web!*** We now include **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

The Medical Nutrition hospitals trust.

Delivered to your door by someone you trust.

Thickened Apple Juice
DIABETISHIELD
IMPACT RECOVER
Strengthen the Immune System For A Faster Recovery
Arginaid

Welcome to the *NEW* Resource® Medical Nutrition Center -
exclusively at www.resource.walgreens.com

Now you can have Resource® Medical Nutrition supplements that hospitals trust - conveniently shipped straight to your home by Walgreens, *The Pharmacy America Trusts®*.

Clinical performance, great taste

Health Care Professionals recommend Resource® Medical Nutrition because it works, but you'll choose Resource® for the way it tastes. All our products come in easy-to-use packaging, making Resource® as simple to enjoy as it is to obtain.

Our prices go down easy, too

Resource® Medical Nutrition products are priced competitively with other brands, and standard shipping is FREE on orders of $50 or more*. Plus, we'll rebate 50% off of one order, up to $20**.

Order now

Visit **www.resource.walgreens.com** or call **1-800-828-9194** to place your order or request a program catalog. You'll discover we not only promise the best Medical Nutrition - we deliver it.

NOVARTIS

NOVARTIS NUTRITION
To improve lives. To extend lives. To save lives.

Walgreens.com®
America's Healthiest Web Site™

We offer Resource® Medical Nutrition for the following health conditions:

General Nutrition Supplements • Before/After Surgery • Cancer • Children's Nutrition • Diabetes • Digestive Conditions • HIV/AIDS • Fluid Restriction/Concentrated Nutrition • Kidney Disease/Dialysis • Pulmonary (Lung) Conditions • Swallowing Problems • Wound Healing

As always, consult a Doctor or Dietitian regarding Medical Nutrition support.

Circle #69 or visit www.eparent.com/adinfo

---

*Subtotal excludes prescriptions, taxes and shipping
**Novartis Nutrition mail-in rebate offer
Not available in Walgreens stores.

©2002 Novartis Nutrition Corporation

A Better Bedtime Story

The Vail Enclosed Bed

Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for your child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt. Plus, we provide assistance in obtaining insurance approval.

Available from home health-care products dealers, or direct from the manufacturer.

For a FREE catalog, call:
1-800-235-VAIL

Vail Meadows Therapeutic Riding Center

Corporate Sponsor of Vail Meadows Therapeutic Riding Center

Happy challenges for challenged riders.

Ask about Our Decorator Accessories.

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

Sheri Wittmer
Sandusky, Ohio

1.102

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard

Circle #86 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent

OCTOBER
2002
$4.95

Annual Toy Issue: Exceptional Achievement Award

Rising Tide of Autism

New Series from AAMR

An Interview with Francis Collins, MD, PhD: Director, Human Genome Project

BEST COPY AVAILABLE

*****************************5-DIGIT 22201
22201AQU111CU00 ZNI02
ACQUISITIONS
ERIC CLEARINGHOUSE
COUNCIL FOR EXCEPT S107 P2
1110 N GLEBE RD STE 300 R= 6642
ARLINGTON VA 22201

www.eparent.com

1103

IBM

Independence.
Empowerment.
That's accessibility from IBM.

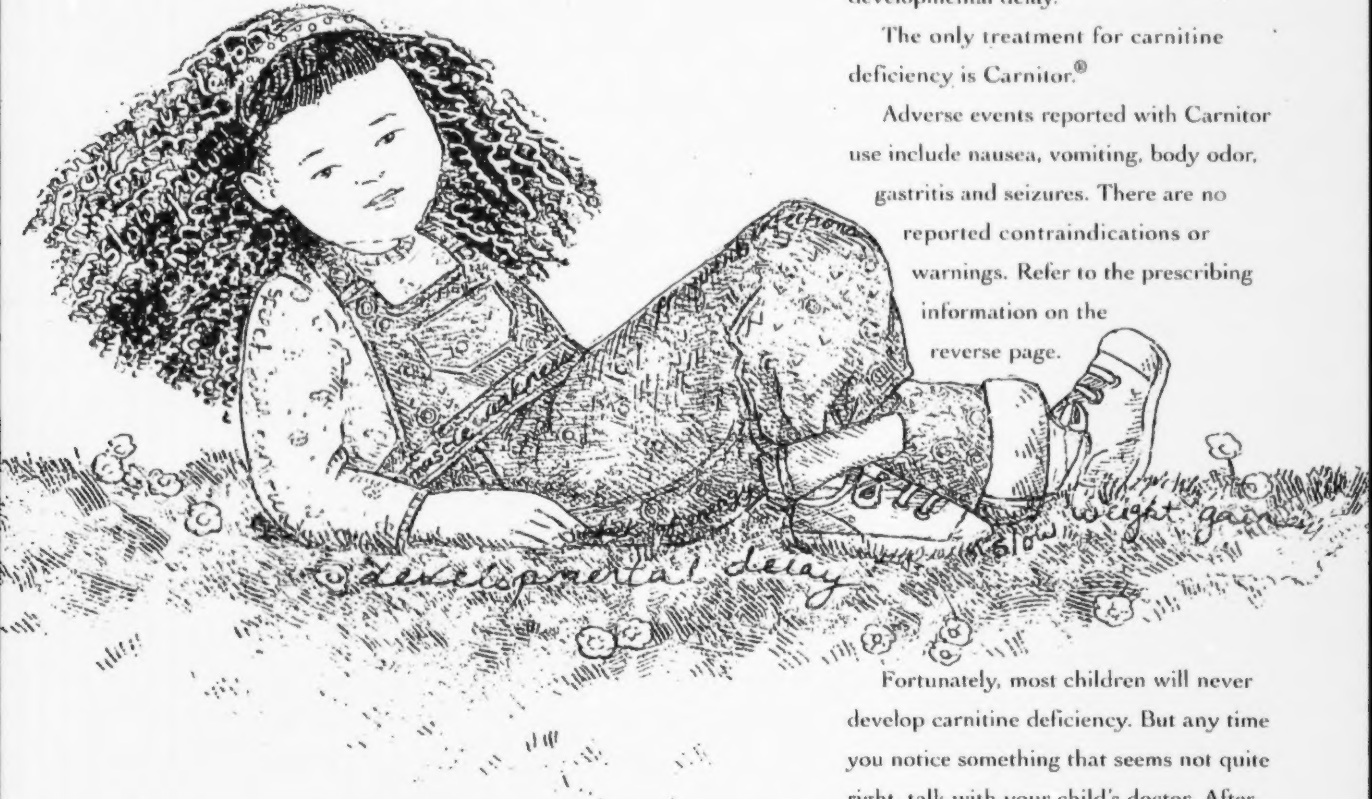
IBM knows the independence accessibility can bring. For over a decade, IBM has pioneered the cause to open the world of information technology to more people, regardless of ability or disability. Our accessibility product solutions have become valued tools for teachers, therapists and people with disabilities. With products such as IBM Home Page Reader, a self-voicing Web browser, IBM has given blind and low vision people greater access to the Web. And our work continues. Soon, we will be doing even more. The vision at IBM is to help people feel more connected, more productive and more empowered in their lives. IBM understands the challenges. We're here to help.

For more information about IBM accessibility solutions, and to download a 30-day trial of Home Page Reader at no charge, visit **www.ibm.com/able**.

IBM is a registered trademark of International Business Machines Corporation in the United States and/or other countries. ©2002 IBM Corporation. All rights reserved.

Circle #78 or visit www.eparent.com/adinfo

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?



No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.

Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

1105

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA 10

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses [illegible] be of benefit. Dosage should start at 1 g/day, (10 m[illegible]y), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #76 or visit www.eparent.com/adinfo

contents

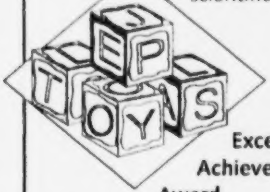
OCTOBER 2002 ◦ VOLUME 32, ISSUE 10

FEATURES

28 Interview with the Director of the Human Genome Project

By Lucinda M. O'Neill

Francis Collins, MD, PhD, Director of the Human Genome Project, discusses the impact on medical research and treatment resulting from this scientific achievement.



35 Toys for all

Exceptional Achievement Award

The ninth annnual Toy Review recognizes the best toys for all and some all-time favorites.

45 She's Got the Beat

By Jennifer Kirby and Lori Ostrover

When Interactive Metronome treatments were effective for her son, Kevin, Dr. Star Anthony became a practitioner herself.

62 CFRI Conference

By Jennifer Block Martin

Ms. Martin reports on the 2002 Annual Meeting of the Cystic Fibrosis Research Institute.

64 Adapted Bikes

By Richard Klein, PhD, Lauren J. Lieberman, PhD, Patrick DiRocco, PhD, and Elaine McHugh, PhD

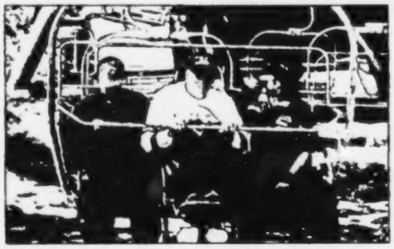
Specially equipped bicycles bring theory into practice in teaching children to ride.

EP Exceptional Achievement AWARD

68 The Magic of Snow

By Dorothy A. Levinson

A personal account of a vacation at a ski resort with facilities for people with disabilities.



72 Disability Awareness Night at Fenway Park

74 Understanding Dysphagia: A Parent's Guide

By Debbie Lord MA, CCC, SLP/L & Lee Barks, RN, MN, ARNP

The first of a series of articles provided by the AAMR (American Association on Mental Retardation).

78 Gynecological and Reproductive Healthcare: for Women with MR/DD

By Catherine A. Kopac, PhD, GNP

An overview of some health issues faced by women with special needs and how their parents and health care professionals can deal with them.

109 The Keys to Ensure Access to Dental Care

By Sanford J. Fenton, DDS, MDS, FDS, RCSEd, FADPD, and Carlton V. Horbelt, DDS, FADPD

Dental care access has been a problem for those with special needs, but organizations at the national, state and local levels continue to try to work out the issue.

AUTISM

50 Autism Overview

The best medical authorities have set out questions about autism that EP magazine will address during the coming months.

56 Summarizing Alternative Treatments

By Laura Apel

With the help of Dr. Mehl-Madrona's research, parents of children with autism can now find a variety of treatments available to help their loved ones.

58 Off-Label Drugs

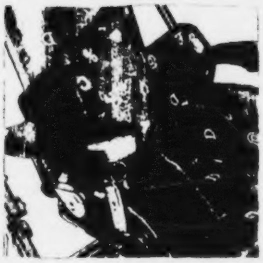
By Julia Steele

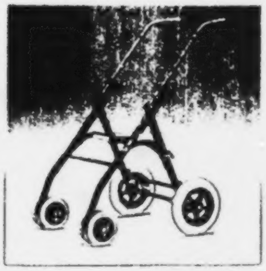
An explanation of off-label drugs and their usage in treatments of disabilities including autism.

ON OUR COVER: Francis Collins, MD, PhD, Director of the Human Genome Project, cradles his seven-hour-old grandson, Sellers Hill.

EP
Exceptional Parent

PANDA FUTURA





R82's Panda Futura is a modular seating system designed for children who require positioning accessories. When combined with our indoor and outdoor mobility bases, the Panda is the ideal product for eating, playing, resting, and transport activities.

A reclining back and tilt-in-space feature positions the body in proper alignment. This enables the caregiver to adjust the seat to meet the changing postural needs of a child throughout a typical day. From an anterior tilt for functional activities, to a reclined resting position the Panda Futura does it all.

Accessories include lateral supports, abductors, vests, belts, harnesses, trays, knee supports, head rests, shoulder retractors, armrests, and a variety of footrest options. Growth pads are included, and optional seat and back extensions can be purchased to enable your child to use this system for several years.

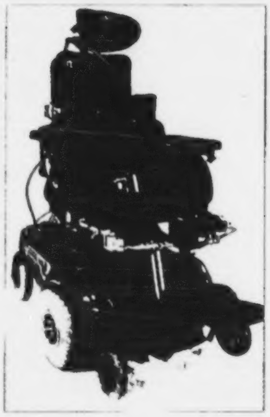
CALL SNUG SEAT NOW FOR YOUR FREE CATALOG

1-800-336-7684

1109

SNUG SEAT®

Circle #68 or visit www.eparent.com/adinfo



contents

DEPARTMENTS

14 **Editor's Desk**

21 **Search & Respond**

26 **Letters to the Editor**

86 **What's Happening**

- In Memoriam
- Airplane Hotline
- Kellogg Scholarships
- Calendar

90 **Org. Spotlight**

The Tuberous Sclerosis Alliance

94 **Research Reflections**

By Jan Blacher, PhD

Autism Rising

102 **Ask the Doctor**

By Frank Manginello, MD

105 **In Depth**

106 **EP Library**

108 **Familiar Faces**

115 **New Products**

116 **Children's Page**

Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy Ed Corp., dba *Exceptional Parent Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy-Ed Corp. *Exceptional Parent*® is a registered trademark of the Psy Ed Corp. **Postmaster:** Please send address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *Exceptional Parent*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #4006 0754. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

Exceptional Parent neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
EP advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative nomenclature.

—Rick Rader, MD

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman, Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing, Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine, Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics , Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof., Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

HAROLD TURNER, D.D.S., Editor Emeritus, Oral Health

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

Quality for life

The Bugsy walker's maximum adjustability and solid, lightweight construction provide safety, convenience, and functionality like no other.

The Bugsy's highly adjustable design encourages active postural control during standing and walking, while also promoting a more natural movement. Unlike other walkers, Bugsy's solid rubber wheels feature stainless steel ball bearings for smooth, easy maneuverability. The anti-reverse wheel design prevents inadvertent backward rolling for safety. Lightweight construction and a quick fold-up feature provide easy handling and storing.

Contact your Otto Bock Sales Representative (U.S. 1-800-328-4058 or Canada 1-800-665-3327) to see the Bugsy pediatric postural walker firsthand.

Otto Bock
HEALTH CARE

www.ottobockus.com
www.ottobockcanada.com

CONTROL

Handlebars are height and depth adjustable to accommodate growth and gait patterns.

Optional positioning aids, such as upright handlebar with forearm pads provide stability and postural support for children unable to use the standard handlebar.

Lightweight and easily folded for added convenience.

Optional swivel wheel locks and rear friction brakes provide directional control and extra safety.

Soft, solid rubber wheels with stainless steel ball bearings provide easy rolling and maneuverability even under heavy pressure.

Optional hip pads and seat

Optional back support and handle grips with wooden stops

Circle #61 or visit www.eparent.com/adinfo

© 2002 Otto Bock Health Care U.S., Inc. Cloud is a trademark of Otto Bock Health Care U.S., Inc. 20020405.4

ACCESS TO ORPHAN DRUGS THREATENED FOR MEDICARE PATIENTS TREATED IN HOSPITAL OUT-PATIENT CLINICS. THOUSANDS OF PATIENTS PLACED AT RISK

EP's mandate is to take a stand on issues when the lives and well being of people with disabilities and special needs are unduly compromised. We do not treat this lightly and only get involved after careful consideration of all the facts. We now find ourselves having to take yet another position on Orphan Drugs and specifically, the most recent proposed cuts in Medicare payments and reimbursement provided to hospital outpatient clinics under the Hospital Outpatient Prospective Payment System (HOPPS).

Let me provide a quick refresher on the issue of Orphan Drugs. Orphan drugs (and related products) are treatments for rare disorders; as defined in the Orphan Drug Act of 1983, a rare disorder is a disease or condition affecting fewer than 200,000 Americans. Pharmaceutical companies and research companies spend millions of dollars developing these products under "fast-track approval" guidelines established by the Food and Drug Administration. This is an expedited process developed to get these drugs to market so that patient lives can be saved and the quality of life improved for those people impacted by the rare and disabling conditions.

On August 9, 2002 Medicare proposed a very serious cut in the payment for 2003 for many drugs provided in hospital outpatient clinics. This proposed cut comes on top of another major cut in payments for drugs used in the hospital outpatient setting of care that was just put in place in April of 2002. What does all of this mean and why should caregivers, physicians, allied healthcare professionals, families and those with special needs be concerned about this?

The answer is quite simple: This is a critical access issue for those rare diseases and conditions where injectable and intravenous treatments are currently available and paid for by Medicare. Many existing orphan drugs, including blood products for individuals with hemophilia and also spasticity arising out of central nervous system disorders, such as cerebral palsy, cervical dystonia and other similar conditions, will become less available beginning in January. This pending legislation, if enacted, may make future treatments (and possible cures) inaccessible. Notably at risk might be promising protein and enzyme therapies for certain genetic disorders. Under the proposed Medicare cuts, treatments for rare disorders will be bundled for payment with high-volume, mainstream drugs that cost considerably less; hospital outpatient clinics will be wary of stocking expensive low-volume drugs such as orphan products if they know that they will not be adequately reimbursed. As a result, patients will be denied treatments because healthcare providers may refuse to administer orphan drugs and biologics to Medicare patients with these disorders and conditions.

Such action by Medicare is not only illogical and unsound but it is clearly insensitive to the basic needs of those with special healthcare conditions. Simply put, Congress should ensure that each orphan drug or biologic is considered individually, not as part of some convenient "bundling" approach because their costs vary widely and they cannot be compared to common drugs used for more prevalent conditions.

You can make a difference and you must make a difference! EP joins the National Organization of Rare Diseases (NORD) and supports its task force focused on expanding awareness of the importance of this issue and facilitating action on your part. You can write letters to your congressman and senators. Sample copies are provided on the EP Web Site along with specific addresses where they can be sent. Simply log onto the EP Web site at http://www.eparent.com and click on "Orphan Drugs". And this appeal transcends those who might be impacted directly. All of us are affected by this kind of shortsighted thinking and all of us have an obligation to support each other.

Don't wait. The time for action is now.

Joseph M Valenzano

Joseph M. Valenzano, Jr.
President CEO & Publisher

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

EDITOR-IN-CHIEF	RICK RADER, MD
CONSULTING MANAGING EDITOR	DONALD P. MAZZELLA
MEDICAL EDITOR	FERN R. POTVIN
SENIOR EDITOR	LAURA APEL
ASSISTANT EDITOR	MEGAN HENNINGER
ASSISTANT EDITOR	ARNOLD KIM
ASSISTANT EDITOR	LORI OSTROVER
ASSISTANT EDITOR	JULIA STEELE
ASSISTANT EDITOR	MARIA TORTORETO
INFORMATION SYSTEMS COORDINATOR	DENNIS DUSEVIC
RESEARCH ASSISTANT	SUSAN JENKINS
GRAPHIC CONSULTANT	DENNIS WILKES
PRESIDENT, CEO & PUBLISHER	Joseph M. Valenzano, Jr.
VP BUSINESS DEVELOPMENT & INTERNET PROJECTS	Vanessa B. Ira
CHIEF FINANCIAL OFFICER	Dolores A. Kinley
AD TRAFFIC MANAGER	Kendra Kelly
SALES COORDINATOR	Doris DeFina
RECEPTIONIST/PUBLIC RELATIONS COORDINATOR	Robyn Sager
ART DIRECTION, DESIGN	Publishers Design Group, Inc. ✉annpdg@aol.com
PRODUCTION MANAGER	Michael Longobardi
EP LIBRARY	Ron Richards (800) 535-1910 ✉eplibrary@aol.com
WEBMASTER	Ken Fleischer, Dynamic Media Works ✉webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Vanessa B. Ira
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 ext. 209
✉ vira@eparent.com
CANADA

Annabelle & Gabe Jacobson
The Lyon Group
806 Lawler Ave.
Wilmette, IL 60091
(847) 256-6850
(847) 256-6819-fax
✉ bellyon@megsinet.net
MI, WI, IA, IL, IN

Bill Joubert
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ bjoubert@superlink.net
MT, ND, MN, SD, WY, NE, KS, OK, TX

Jared Adams
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 ext. 204
✉ jadams@eparent.com
DE, MD, DC, WV, VA, NC, SC, GA, FL, KY, TN, AL, MS, LA, AR, MO

Matt Valenzano
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 ext. 211
✉ mattvalenzano@eparent.com
ME, VT, NH, MA, RI, CT, NY

Brian Regan
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
brianregan@sprintmail.com
PHARMACEUTICALS

Larry Battistello
Marketing Plus
3155 East Ramon, Unit #203
Palm Springs, CA 92264
✉ scene-lads@aol.com
(760) 320-8797
(760) 320-9728-fax
TERRITORY: WA, OR, ID, NV, CA, UT, CO, AZ, NM, AK, HI

Barbara Nastro
65 East Route 4
River Edge, NJ 07661
(908) 534-6366
(908) 534-6941-fax
✉ nastro@blast.net
NJ, PA, SCHOOLS, CAMPS & RESIDENCES, MARKETPLACE

COLOR SEPARATION/FILM PREPARATION
AGT7 Carlstadt, NJ 07072

LIST RENTALS
GRS
Mktg Services Inc.
187 Billardvale Street
Wilmington, MA 01887
Attention: Mark Hammar
978-661-8126
mhammar@mktgservices.com

PUBLISHING & EDITORIAL OFFICE
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

SUBSCRIBER SERVICE:
EXCEPTIONAL PARENT
P.O. Box 2078, Marion, OH 43306-2178.

CUSTOMER SERVICE/NEW ORDERS:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

EXCEPTIONAL PARENT magazine was founded in 1971 by Maxwell J. Schleifer, PhD

For subscription and advertising information, see page 98

Johnny, 51 lbs. and 48" tall, in the Columbia Car Seat

Sharing the Caring

Columbia offers you solutions to the daily challenges of transporting, bathing and toileting your child – *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

▨ When your child has outgrown that infant car seat, you can have peace of mind knowing that the **Columbia Car Seat** has been crash tested for children from 20 to 102 lbs.–yet weighs only 11 pounds! It has been the No. 1 choice since 1986, for its adjustability and stylish comfort.

#2000 Car Seat

▨ At bathtime, our popular **Reclining Chairs** and **Wrap-Around Bath Supports** allow your child – and you – to enjoy the bath.

#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.

#7700 Hi-Back Wrap-Around Support

☐ At toileting time, our **Toilet Supports** fit easily onto any toilet; remove easily, too. And our **Positioning Commodes** give the same toileting support in any location.

Why do these products work so well? Columbia products are thoughtfully designed, with each item available in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, tested and proven in real-life experience. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

#4200 Small Support for children

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

COLUMBIA
SHARING THE CARING

Circle #26 or visit www.eparent.com/adinfo

CALL 1-800-454-6612 TODAY FOR YOUR FREE CATALOG
Columbia Medical Mfg. Corp., Dept D1, P.O. Box 633, Pacific Palisades, CA 90272
Visit Our Web Site at http://www.ColumbiaMedical.com

BRADY | EPILEPSY
DAILY SEIZURES
MULTIPLE MEDICATIONS
FLUNKING SCHOOL
EXHAUSTION
ER VISITS EVERY MONTH
FALLING
LIVING IN A HELMET
A SEIZURE EVERY FEW MONTHS
ONE MEDICATION
ALL B'S
ENERGY
ONE ER VISIT LAST YEAR
FOOTBALL
HANGING OUT WITH THE GUYS

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

1116

BEST COPY AVAILABLE

VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS THERAPY™

VAGUS NERVE STIMULATION

Cyberonics®

Circle #30 or visit www.eparent.com/adinfo

1115

EXECUTIVE SUMMARY[1]
SAFETY INFORMATION
FOR THE NCP® SYSTEM

INTENDED USE / INDICATIONS – UNITED STATES

The NCP System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures which are refractory to antiepileptic medications.

CONTRAINDICATIONS

- The NCP System cannot be used in patients after a bilateral or left cervical vagotomy.
- Do not use short-wave diathermy, microwave diathermy, or therapeutic ultrasound diathermy on patients implanted with the NCP System. . Diagnostic ultrasound is not included in this contraindication.

WARNINGS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals. This is not intended to serve as a substitute for the complete NCP System Physician's Manual.

⚠ The **safety and efficacy** of the NCP System has not been established for uses not covered in the "Intended Use/ Indications" section of the manual.

⚠ The safety and efficacy of the NCP System treatment has not been established for stimulation of the **right vagus nerve** or of any other nerve, muscle, or tissue.

⚠ **Excessive stimulation** at a combination of high frequency (≥ 50 Hz) and an excess duty cycle (that is, one that occurs when ON time is greater than OFF time) has resulted in degenerative nerve damage in laboratory animals. An excess duty cycle can be produced by continuous or frequent magnet activation (> 8 hours), as determined by animal studies. Cyberonics recommends against stimulation at these combinations of ranges.

⚠ **Aspiration** may result from the increased swallowing difficulties reported by some patients during stimulation. Patients who have **pre-existing swallowing difficulties** are at greater risk for aspiration.

⚠ **Device malfunction** could cause painful stimulation or direct current stimulation. Either event could cause nerve damage and other associated problems. Patients should be instructed to use the magnet to stop stimulation if they suspect a malfunction, and then to contact their physician immediately for further evaluation. Prompt surgical intervention may be required if a malfunction occurs.

⚠ Susceptible patients with predisposed cardiac conduction systems (re-entry pathway) have not been studied as part of controlled clinical trials to establish the safety of NCP system treatment in these patients. Evaluation by a cardiologist is recommended if the family history, patient history, or electrocardiogram suggests an abnormal cardiac conduction pathway. Serum electrolytes, magnesium, and calcium should be documented before implantation. Post-implant electrocardiograms and Holter monitoring are recommended if clinically indicated.

⚠ **Sudden unexplained death in epilepsy (SUDEP)**: Through August 1996, 10 sudden and unexplained deaths (definite, probable, and possible) were recorded among the 1,000 patients implanted and treated with the NCP device. During this period, these patients had accumulated 2,017 patient-years of exposure. Some of these deaths could represent seizure-related deaths in which the seizure was not observed, at night, for example. This number represents an incidence of 5.0 definite, probable, and possible SUDEP deaths per 1,000 patient-years. Although this rate exceeds that expected in a healthy (nonepileptic) population matched for age and sex, it is within the range of estimates for epilepsy patients not receiving vagus nerve stimulation, ranging from 1.3 SUDEP deaths for the general population of patients with epilepsy, to 3.5 (for definite and probable) for a recently studied antiepileptic drug (AED) clinical trial population similar to the NCP System clinical cohort, to 9.3 for patients with partial onset epilepsy.

⚠ **The NCP device is not curative**: Physicians should warn patients that the NCP System is not a cure for epilepsy and that since seizures may occur unexpectedly, patients should consult with a physician before engaging in un-supervised activities, such as driving, swimming, and bathing, and in strenuous sports that could harm them or others.

⚠ **Obstructive Sleep Apnea**: Patients with obstructive sleep apnea (OSA) may have increased apneic events during stimulation. Cyberonics recommends care when treating patients with preexisting OSA. Lowering stimulus frequency or prolonging OFF time may prevent exacerbation of OSA.

PRECAUTIONS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals.

⚠ **Laryngeal irritation** may result from stimulation. **Patients who smoke** may have an increased risk of laryngeal irritation.

⚠ **Dyspnea** may result from stimulation. **Patients with chronic obstructive pulmonary disease** may have an increased risk of dyspnea.

⚠ It is important to follow **recommended implantation procedures and intraoperative product testing** described in this manual. During the intraoperative Lead Test, rare incidents of bradycardia and/or asystole have occurred. As of October 1998, approximately 3,000 patients had been implanted with the NCP System. Four of these patients were reported to have experienced **bradycardia and/or asystole** during the intraoperative Lead Test. All four patients recovered without sequelae. One of the four patients was implanted with the NCP System. There were no postoperative or VNS-treatment-related cardiac adverse events later reported for that patient. No similar events were reported to have occurred during the clinical studies at the time of implantation or during treatment. The safety of this therapy has not been systematically established for patients experiencing bradycardia or asystole during NCP System implantation.

⚠ **Reversal of lead polarity has been associated with an increased chance of bradycardia** in animal studies. It is important to make sure that the Lead connector pins are correctly inserted (white marker to + connection) into the Pulse Generator header.

⚠ It is important to follow **infection control procedures**. Infections related to any implanted device are difficult to treat and may require that the device be explanted. Cyberonics recommends that the patient be given antibiotics preoperatively. The surgeon should ensur that all instruments, including the NCP Tunneling Tool, are sterile prior to the operation.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve** in the neck area inside the carotid sheath.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve below where the superior and inferior cervical cardiac branches separate from the vagus nerve.**

⚠ A **neck brace** can be used by the patient for the first week to help ensure proper Bipolar Lead stabilization.

Environmental and Medical Therapy Hazards

⚠ Patients should exercise reasonable caution in avoiding devices that generate a **strong electric or magnetic field.** (For examples, see the "Other Environmental Hazards" section of the Physician's Manual.) If a Pulse Generator ceases operation while in the presence of electromagnetic interference (EMI), moving away from the source may allow it to return to its normal mode of operation.

⚠ NCP System operation **should always be checked** by performing device diagnostics after any of the procedures mentioned in the Physician's Manual.

⚠ Because of where the Pulse Generator is implanted in the chest, **patients may need to be specially positioned in mammography equipment for clear imaging.** Otherwise, the device may be seen as a shadow on the mammogram. (Most routine diagnostic procedures such as fluoroscopy and x-radiography, are not expected to affect system operation.)

⚠ **Therapeutic radiation** may damage the Pulse Generator's circuitry, although no testing ha been done to date and no definite information on radiation effects is available. Sources of such radiation include therapeutic x-rays, cobalt machines, and linear accelerators. The radiation effect is cumulative, with the total dosage determining the extent of damage. The effects of exposure to such radiation can range from a temporary disturbance to permanent damage, and may not be detectable immediately.

⚠ **External defibrillation** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for external defibrillation.

⚠ **Electrocautery surgery** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for electrocautery surgery.

⚠ **Magnetic resonance imaging** (MRI) should not be performed with a magnetic resonance body coil in the transmit mode. The heat induced in the Bipolar Lead by an MRI body scan can cause injury.

Use caution when other MRI systems are used, since adverse events may occur because o different magnetic field distributions

⚠ No scan in which the radiofrequency (RF) is transmitted by the body coil should be done on a patient who has the NCP System. Thus, protocols must not be used which utilize local coils that are RF-receive only, with RF-transmit performed by the body coil. Note that some RF head coils are receive only, and that most other local coils, such as knee and spinal coils, are also RF-receive only. **These coils must not be used in patients with the NCP System.**

⚠ **Therapeutic ultrasound.** Routine therapeutic ultrasound could damage the Pulse Generator and may be inadvertently concentrated by the device, causing harm to the patient.

⚠ **Extracorporeal shockwave lithotripsy** may damage the Pulse Generator. If therapeutic ultrasound therapy is required, avoid positioning the Pulse Generator part of the body in the water bath or in any other position that would expose it to ultrasound therapy. If that positioning cannot be avoided, program the Pulse Generator output to 0 mA for the treatment, and then after therapy, reprogram the Pulse Generator to the original parameters.

Diagnostic ultrasound is not expected to affect the NCP System.

⚠ The Pulse Generator may affect the operation of **other implanted devices,** such as cardia pacemakers and implantable defibrillators. Possible effects include sensing problems and inappropriate Pulse Generator responses. If the Pulse Generator patient requires concurrent implantable pacemaker and/or defibrillator therapy, careful programming of each system is necessary to optimize the patient's benefit from each device.

ADVERSE EVENTS

Adverse events reported during clinical studies as statistically significant are listed in alphabetical order Ataxia (muscle movements or twitching, generally associated with stimulation); Dyspepsia (indigestion); Dyspnea (difficulty breathing, shortness of breath); Hypesthesia (impaired sense of touch); Increased coughing; Infection; Insomnia (inability to sleep); Laryngismus (throat, larnx spasms); Nausea; Pain; Paresthesia (prickling of the skin); Pharyngitis (inflammation of the pharyn throat); Voice alteration (hoarseness);Vomiting.

Other potential adverse events possibly associated with surgery or stimulation include but are no limited to the following:

Aspiration (fluid in the lungs); Blood clotting; Choking sensation; Damage to nerves or vasculature i the surgical area, including the carotid artery and jugular vein; Device (Generator and/or Lead) migration or extrusion; Dizziness; Dysphagia (difficulty swallowing); Duodenal ulcer, gastric ulcer; Ear pain; Facial flushing; Facial paralysis, paresis; Foreign body reaction to implants, including possible tumor formation; Formation of fibrous tissue, pockets of fluid; Heart rate and rhythm changes; Hiccuping; Incision site pain; Irritability; Laryngeal irritation (sore, painful throat); Left hemidiaphragm paralysis; Left recurrent laryngeal nerve injury; Left vocal cord paralysis; Low-grade fever; Muscle pain; Neck pain; Nerve injury; Painful or irregular stimulation; Skin, tissue reaction; Stomach discomfort; Tinnitus (ringing in the ears); Tooth pain; Unusual scarring at the incision site; Urinary retention; Vagus nerve paralysis; Weight change; Worsening of asthma and bronchitis; Worsening of cardiac abnormalities, including heart rate and rhythm.

⚠ Patients who manipulate the Pulse Generator and Bipolar Lead through the skin may damag or disconnect the Bipolar Lead from the Pulse Generator and/or possibly cause damage to th vagus nerve.

---

[1] The information contained in this Executive Summary for Physicians represents partial excerpts of important prescribing information taken from the *NCP Pulse Generator Physician's Manual*. The information is not intended to serve as a substitute for a complete and through understanding of the material presented in all of the Physician Manuals for the NCP System and its component parts nor does this information represent full disclosure of all pertinent information concerning the use of this product, potential safety complications, or efficacy outcomes.

ORIGINAL
EDENSOY
ORGANIC SOYMILK
EDEN 8.45 FL OZ 250ML
EDEN ORGANIC
GREAT NORTHERN BEANS
No Salt Added Low Fat
EDEN ORGANIC
APPLE JUICE
EDEN ORGANIC
Vegetable Alphabets

EDEN®

Our Children... Our Hearts

Nurture them with Good Food.

At Eden this means: no irradiation, no preservatives, no chemical additives, no food colorings, no refined sugars, no genetically engineered ingredients ~ the safest, most nutritious, certified organically grown food that can be acquired.

More than 200 EDEN® foods are available at discerning retailers in the U.S.A. and Canada.

Pure Food is Our Passion, Great Taste is Our Joy.

Ⓚ parve

on of an Eden
Production
Supervisor

Visit **www.edenfoods.com** for over 500 free recipes and product information.

© 2002 Eden Foods, Inc., Clinton, Michigan 49236 • info@edenfoods.com • 888.424.EDEN

Circle #34 or visit www.eparent.com/adinfo

Persistence

People with incredible burdens, chronic disorders, bad biopsies, complex disabilities and blurred horizons. They are patients, persistent patients. People who endorse Merel Meacham's observation that "In the fight for survival, a tie or a split decision simply will not do." What's with this persistence?

The word persistence is appropriately sandwiched in between the definitions of a fine hard wood tree (persimmon) and a human being (person). How exquisite this is. For, indeed, that's what being persistent is all about. It's about having unique qualities of an individual with the resolute posture of an unwavering tree. Deep-rooted trees are there for the duration. They are hard to intimidate, hard to rattle, hard to shake. And unless there is some cataclysmic natural event, chances are that the tree will see many seasons come and go. Just like people with persistence. People who began where they found themselves.

I cannot recall the first time I heard the expression, "Hang in there." Whenever it was, I know that it must have paralleled some adversity I was struggling with- or at least the perception of a struggle- by a supportive bystander. Maybe it was when I was running "wind-sprints" on a hot, August, pre-season college football camp drill-grunting, heaving, gasping for breath, clutching my side, and trying to spit through my facemask. More probably it was going into my neuro-anatomy final exam in medical school, having spent the previous twenty-eight hours trying to familiarize myself with non-concrete neural pathways that made as much sense to me as the wiring diagram of 1927 Rickenbacker tourer. Or perhaps while being wheeled into surgery hoping to outmaneuver a rogue polyp that had decided to form its own renegade malignant outposts.

"Hang in there." The words are emblematic of a philosophy and belief that if you persevere, you are bound to succeed. But we know better. As comforting as they may be, those words offer no garnets. There are no formulas for rising above adversity. Max Lerner was fond of remarking, "Somehow life doesn't always pay off to those who are most insistent." Just read the obituary columns in any newspaper on any day: ".... Died after long courageous battle against...,""... passed away after waging an admirable fight..." Sure they were fighters-and persistent ones at that-but in the end, they did not make it. There are no guarantees that a fired-up will count's for all that much. In fact, the expressions " sweet surrender," " let yourself go," and "don't fight it anymore" are by-words in many hospice scenarios.

Robert Frost's insistence that " the best way out is always through" does not always apply in every situation. Especially when you do not want "out." One quickly learned multiple-choice-test-taking rule in medical school was never to opt for the "never" and "always" choice. Those words have never occupied a safe domain in medicine. It only takes one unanticipated outcome, one surprise, one red herring, one zebra, one miraculous eleventh-hour turnaround to relegate "never" and "always" to the tundra of "we can't know or say that for sure." Medicine, mind you, has never claimed to be an exact science. And despite the emergence of Buck Rogers technology, the "art part" of the art and science of medicine still plays an important role in many successful outcomes.

It is interesting that, despite the acknowledgment by clinicians that " persistent patients" are indeed a viable and distinct entry-in fact, worthy of doctors documenting that distinction under their "clinical impressions" (almost like the "allergy red flag" marks on charts)-the phrase itself receives little exposure in medical literature. The two most popular uses of the term "persistent" (which is not found in any medical dictionary, by the way) is its descriptive use in "persistent pain" and " vegetative state." Neither alludes to the positive attributes and qualities of the "persistent patient."

Sometimes medical education is slow on the uptake. It took hundreds of years for physicians to include in their bedside clinical presentation brief insightful descriptions that relate to the "patient" outside his or her diseased state. "Patient appears to be younger than his stated age," "patient seems to be a reliable informant," patient appears histrionic," or "the patient has a good sense of humor." It would, indeed, take an astute medical student to open his Grand Rounds presentation with "Mr. Jeffries is a fifty-three-year-old, white male who presents with a persistent demeanor and a...." That description honors Mr. Jeffries and, perhaps, would change the management of his case and his relationship with the clincians treating him.

As we used to say in medical school, Bet'cha there's a journal article here somewhere."

There is a popular expression that has made its way onto bumper stickers, T-shirts, and brick buildings, "S——happens ." It described the role of chaos in everyday life, the throw of the dice in genetics, being in the wrong place at the wrong time, the unpredictability of the " happenstance of the natural world." It explains the Rube Goldberg-like connectivity of everything to everything. It is concise and universally understood. It remains a masterpiece on the economy of words. " S——happens." Indeed.

The mythological character Hercules and the African dung beetle seemingly would not have much to share over a beer. But by the third bowl of pretzels each would recognize the other as personifying the quality of persistence. Hercules had to be persistent in cleaning the Augean Stables (his sixth labor); heck, they contained three thousand cattle and had not been cleaned for thirty years. Now that is persistence. And how about that dung beetle: pushing that dung sphere (four times his size) over the arduous African terrain for miles in search of a secure mating site (location,location,location). But common, ordinary people demonstrate examples of comparable persistence every day, too.

> *"I am a kind of burr, I shall stick"*
>
> **William Shakespeare**

And it happens in Africa's Okavanga Swamp, south-central Los Angles, nuclear reactors, jazz improve sessions, and most assuredly, in molecular biology. Cells do or do not divide, blood flows or not, killer cells do or do not get off of their duffs. "S—happens," and so does oxygenation, filtration, neurotransmission, and cell scavenging. Sometimes it happens when the clinical wisdom of collective experience dismisses the possibility. It happens long after the white coats stop expecting and hoping for it. It happens (but not often enough) after it has been deleted from the clinicians' short list of expected outcomes.

One of medical science's most significant challenges is explaining the unexplainable, even when meeting with an astonished family gathered around the ICU bed of a loved one. The shock of loving family members is often expressed in the term "It happened," yet the medical team is mandated to dig deeper and answer the question "Why?"

A family viewing their sixteen-year-old linebacker miraculously emerging from a football-injury-induced coma could not care less about her histochemical changes in enzymes of energy metabolism in the dentate gyrus.

The family of a once-jovial, engaging grandfather with Parkinson's disease rejoices in an unexplained return to his pre-affliction steady gait and controlled movements. Their joy preempts any interest for the possible role of calcium and nitric oxide as early mediators of neurotoxicity. The relatively young science of psychoneuroimmunology exists to provide the " hard science" behind the milestones of the persistent patient. This discipline addresses the axis between the body's natural immune system and the complex cascade system that is in place to activate or fortify it. While the Reader's Digest showcases astonishing stories about patients' victories over catastrophic and devastating conditions, the New England Journal of Medicine reports on the re-perfusion and cyto-protective windows of brain cells.

Each in its own fashion is celebrating the adventures of the persistent patient-each hoping that it will help in replication stories of persistent Patient profiles. The persistent patient does not have to achieve (and more times does not) spontaneous and complete recovery to reap the benefits of their never-say-never stamina and determination. The persistent patient's reward very often achieved in the psychosocial arena without any change in their physiology. A stronger sense of self, the exhilaration of being a partner in one's own destiny, and the authenticating feeling of calling the shots is often enough. Success for the persistent patient is not hearing the chairperson of the department of medicine say " You were right we were wrong." It's not about one-upmanship or about final scores. It is about revering life and demonstrating to the world that, despite drawing the short straw, individuals can rise to the occasion and make a difference in their own existence. It is about being an ordinary person until your shoulder is tapped and the game starts anew. It is being a person who embraces the wisdom of Sara Teasdale when she decided that she would " make the most of all that comes and the least of all that goes." It is also demonstrating the resilient quality of the human spirit that somehow allows ordinary people to accomplish extraordinary things.

In my own field of developmental disabilities and habilitation, I do not see persistent patients. For one thing, since developmental disabilities are conditions not diseases, we first and foremost do not see the individuals we serve as patients. They are not patients until they break an arm, spike a fever, or get cancer or pneumonia or anything else that begins the medical machinery. Our Clients, in addition to having complex physical and neuro-developmental disorders, are also cognitively challenged. They are often non-vocal (but certainly not non-communicative).

continued on page 19

HARD MANUFACTURING

AGE APPROPRIATE BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas

The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #42 or visit www.eparent.com/adinfo

EP

has the
information an
"Exceptional
Parent"
like you
needs

EP
Exceptional
Parent

Your paid
subscription includes
the EP
2003
Annual
Resource
Guide,
which
normally sells
nationally for $19.95.

This invaluable reference tool is a "must-have" for exceptional parents

Save $5.00
by ordering on-line at:
www.eparent.com
For telephone orders call:
877-372-7368

Circle #199

Subscribe and be part of a network of "Exceptional Parents"

EP
Exceptional
Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______ Exp. Date ______
Name ______
Address ______
City ______ State ______ Zip ______
E-mail ______ Yes, I want more information to help me everyday.
Signature ______ E-mail ______

BOCT2

Subscribe and be part of a network of "Exceptional Parents"

EP
Exceptional
Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______ Exp. Date ______
Name ______
Address ______
City ______ State ______ Zip ______
E-mail ______ Yes, I want more information to help me everyday.
Signature ______ E-mail ______

BOCT2

Make someone a part of a network of "Exceptional Parents"

EP
Exceptional
Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95
☐ 2 Years (24 issues) $65.95
☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year.
Other foreign countries $57.95 per year.

PLEASE SEND MY GIFT OF EP TO:

Name ______
Address ______
City ______
State ______ Zip ______

THIS GIFT IS FROM:

Name ______
Address ______
City ______
State ______ Zip ______

☐ Check enclosed. (use separate envelope) ☐ Bill me later.
☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)
Account Number ______
Exp. Date ______
Signature ______

Save more money: Order off the Web: www.eparent.com

XOCT2

1121

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer life for themselves and for their children.

Exceptional Parent's MISSION

IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

continued from page 15

Our clients are as persistent in their endeavors as any of the more traditional persistent patients showcased in this book. The stamina, fortitude, and endurance are remarkable. They are "persistent" in their diligence in learning new skills and in experiencing new relationships and environments. They are persistent in taking offered risks with the inherent failings and victories that risks relish. Pound-for-pound, they would give anyone a run for their money in the persistent game.

Working with "persistent people" (or, in more appropriate "people first" jargon, "people with persistence") with developmental disabilities has provided an added bonus. One cannot venture very far into the area of working with Children with Special Health Care Needs without reaping the reward from meeting "persistent parents." This last group of the three "p's" in the pod (along with persistent patients" and "persistent physicians/providers") is often the most exciting of the trilogy.

Elizabeth Stone's remarks about parents most certainly had to be directed at parents of children with chronic healthcare needs: "Making the decision to have a child-it's momentous. It is to decide forever to have your heart go walking around outside of your body." Whenever the motivation, character, and grit exhibited by persistent patients, persistent parents have it in spades. In addition to having the identical agenda of the persistent patient, the persistent parent has further distinguishing features. For one, they very often are "speaking" for their children. Coupled with the dynamism of unconditional love, parent-to-parent networking, undergo advocacy and unparalleled energy, the persistent parent is a force to reckon with and admire. These "exceptional parents" have in their cross hairs, at any one time, school administrators, bureaucrats, managed-care nay-sayers, aloof clinicians, and clueless insurance company personnel-in short, the other "p's" in the pod: payers, providers, and policymakers." Persistent parents have changed bus schedules, doorway dimensions, menus, definitions, attitudes, policies, and the law. They have had impact on research, therapies, funding, philosophies, and behavior. Perhaps their greatest achievement is that which is often described as the most challenging of all human endeavors-moving people to action!

Lorenzo's Oil, the Katy Beckett waiver, the Ryan White rulings, NORD, IDEA, ADA, Family Voices, Project DOCC, Exceptional Parent magazine all serve as testimonies to the power of parent persistence. They all stand as tributes to programs initiated by parents whom individually acknowledge that the prevailing landscape was inappropriate and needed to be changed. All significant in that those needed changes had to be carried out by parents, not politicians, professional lobbyists or deep-pocketed special interest groups. Parents. Powerful and provoked. Passionate and progressive. And always persistent. They teach and inspire me, and I unashamedly acknowledge sucking energy from them almost daily.

Persistent patients and parents are rare. Indeed, the insurance companies bank on the ordinary-to-persistent ratio daily. They understand that, if they deny reimbursement to one hundred patients and ninety-five of them go away, they have executed a sound financial strategy. Out of the remaining five, perhaps three will drop out after the third appeal is denied. The two remaining persistent patients will be paid off. Unbeknownst to the bean-counters those two "maverick" patients will serve as templates for other patients. Those two persistent patients will fuel the fires of the next batch of one hundred patients.

Persistent patients-their stories and inspiration-do not necessarily follow the computations and equations of the balance-sheet set. They often function in geometric not arithmetic progressions, defying the calculus of the actuaries. They work in the economy of passion, using the currency of determination and example. They are never quiet about their transactions and victories. Bragging rights are one of the rewards of the persistent patient, as this collection demonstrates.

Adele's tales of ordinary people refused to go gently into the night is a compelling read, not only for patients who find the pathway to persistence to be a most attractive byway, but for others as well. Plumbers, poets, painters, physicians, and puppeteersæanyone who wants to join the ranks of D.H. Lawrence's "wild things" and believes as he did that: "I never saw a wild thing sorry for itself."

H.L. Mencken said, "Every normal man must be tempted at times to spit on his hands hoist the black flag, and begin slitting throats." Persistent patients slit throats; the throats of ignorance indifference, hopelessness, indignity and ultimately fear. May readers of this book, at the right time, be inspired to hoist that black flag to new heights. EP

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

THANK YOU

FROM THE WORLD CONGRESS & EXPOSITION ON DISABILITIES

We would like to take this opportunity to thank everyone for their participation in and support of the WCD. For all of you who care so much about the welfare and lifestyle of people with special needs, we truly appreciate your contributions.

Special thanks goes out to EP Magazine, as well as the EP Foundation for Education, Inc.; Sigma-Tau Pharmaceuticals; the Florida Division of Vocational Rehabilitation; the Agency for Workforce Innovation; Florida ARF; PALAESTRA Magazine; FAAST, Inc.; America's Athletes with Disabilities; Office of Rare Diseases, National Institutes of Health; Allergan; Genzyme; Merrill Lynch; McDonald's Corporation; and all of our valued sponsors, exhibitors and attendees.

See you again in September

when the WCD will be returning to Orlando,
September 18 - 20, 2003!

---

www.wcdexpo.com
877-923-3976
wcdinfo@wcdexpo.com

1124

BEST COPY AVAILABLE

Circle #77 or visit www.eparent.com/adinfo

Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: EP Magazines, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Down Syndrome and Obsessive/Compulsive Disorder

My son is ten years old and has Down syndrome. He exhibits signs of obsessive compulsive disorder, including stopping to check and recheck his actions, and often beginning again when there was nothing wrong in the first place. The resulting 'obsessive slowness' is disruptive to family life at times, and evokes frustration in all of us, which in turn is not good for our son. What is known about OCD and Down syndrome? Does anyone else also have experience with this or have any suggestions on how to help my child, especially regarding his 'obsessive slowness' behavior?

—LM via EP Web Site

S

Aggressive Social Behavior

My child was born at term with an abdominal malformation, and subsequently had a surgical repair under general anesthesia and a lengthy stay in the NICU. Now, I am looking for any information on treatments used to manage impulsive and aggressive social behavior in an otherwise competent child. If anyone can recommend publications or clinicians to turn to, that would be great.

—CB, via EP Web Site

S

Technology Help

I need assistive technology help. There are thousands of internet sites and hundreds of companies and I am having difficulty sorting through the maze. Generally, if people could recommend a few web sites, that would help. Specifically, I need to know what kind of computer to get for my home, one that would enable us to use the internet and that would also be compatible with having a cause-and-effect device installed for programs.

—DM via EP Web Site

S

Swim Diapers

I am looking for a swim diaper to fit an adult-sized 12-year-old. We have recently found a floatation suit that allows our son to go back into the pool, but his *Attends* bulk up. I need an alternative to a disposable diaper for his swim outings. I know of many other parents who are looking for the same thing. Any ideas?

—CD via EP Web Site

S

Reading Programs

I am working with a 10-year-old girl with autism and I need help on tutoring her with reading. She reads on a first or second grade level. She has done Lovaas programming. She will be going into a fourth grade classroom in the fall. If anyone has ideas, please contact me.

—B via EP Web Site

S

Behavior Problems in Traffic

I have a 10-year-old son with cerebral palsy. He is non-ambulatory. We have a conversion van equipped with a lift so that he can be transported in his motorized wheelchair, but traveling with our son is becoming almost unbearable. If we should get caught in congested traffic and need to slow down, he will start to cry and scream and will not stop until we can pick up speed and move again. This behavior is taking its toll on the entire family! My other two children do not want to travel with their brother. And there is a strain on my relationship with my husband when our son starts to cry and scream. No amount of comforting or reasoning seems to help. When we are preparing for a long trip, I try to talk and reason with our son prior to the trip. He says he is sorry, but once we hit the traffic jam or slow down for some other reason, he starts crying as if he is terrified or something is hurting. After the episode, I try talking with him to find out why he cried, and he can't seem to tell me. Does anyone have any suggestions to help us all out when traveling? Our nerves are just about shot. Thank you.

—GD, via EP Web Site

continued on page 22

Search & Respond

continued from page 21

Seizure Treatment Options

My two-and-a-half-year-old son has CP, a severe swallowing disorder, and a seizure disorder. His seizures respond to seizure medications, but because he is non-verbal he cannot tell us of side effects. The last medicine, Keppra, caused nausea and gagging, and consequently worsened his gastroesophageal reflux. Because of the swallowing disorder, he aspirated and has had tracheitis (he has a tracheostomy tube in place) more often than not. We monitor him vigilantly, but it can take time for us to make a thorough analysis of what is going on with him. In the meantime, he is uncomfortable, sick, and in danger. What other treatment options exist, other than these medications with their side effects, to alleviate seizures? I've heard of the ketogenic diet, although I don't know much about it. How about natural supplements? By solving one problem we exacerbate another. I'm eager for any help or advice.

—NS, via EP Web Site

Supportive Backpacks

My son, nearing his third birthday, weighs just over 30 pounds and is about 3 feet long. He has mixed tone, arching sometimes, floppy at others. I am looking for a back pack that can hold him and give him the support he needs, including head support. I want to be able to take him for a hike in the forest. Any ideas?

—NS, via EP Web Site

Aicardi Syndrome Information

My two-month-old daughter has been recently diagnosed with Aicardi syndrome. Information on this is very limited. I am looking for information and support from other families with daughters who have this syndrome. I am very interested in information for seizure control.

—CM, via EP Magazine

Dr. Feudtner's suggested website:
http://www.aicardi.com/

Safety

Our six-year-old suffered brain damage at three months after being shaken by a daycare provider. He is developmentally delayed and has partial paralysis on the right side, although he can walk with an AFO. Developmentally he is about three. We need to move him out of his crib but are debating which is better: to get a bed that contains him so he cannot hurt himself playing with electrical outlets or to have the outlets covered or moved high on the wall. We would like suggestions from those who have faced a similar dilemma.

—NH, via EP Web Site

Aggressive Sleep Movement

I have a three-and-a-half-year-old son with CP who cannot walk or talk. He wakes up every night at about 3:30 am. His eyes are still shut but his arms and legs go a mile a minute and he cries. I have tried to talk to his doctors but they can't find anything. Anyone have suggestions?

—GM, via EP Web Site

Looking for Support

I am the mother of a nine-year-old boy who has cerebral palsy and a history of epilepsy (seizure free since brain surgery in 1995). He was doing very well up until October of last year, walking with help at the parallel bars, his speech improving, and his overall health wonderful. Then, overnight, everything just went crazy. He can no longer eat normal food, needing it to be pureed. He cannot stand to be touched, crying every time we just start to come near him. He is just slipping so fast and no one can tell us what has happened. He has been through several tests and they have all been normal. For that we are grateful, but we still don't know what has caused him to regress. If anyone has gone through something like this please feel free to email me. We would deeply appreciate talking with anyone who could possibly help us.

—TG, via EP Web Site

Rett Syndrome

Where can I find information online about Rett syndrome? Someone was describing it to me, and since my child is undiagnosed, the brief description I heard was very interesting to me.

—HL, via EP Web Site

Dr. Feudtner's suggested website:
http://www.rettsyndrome.org/

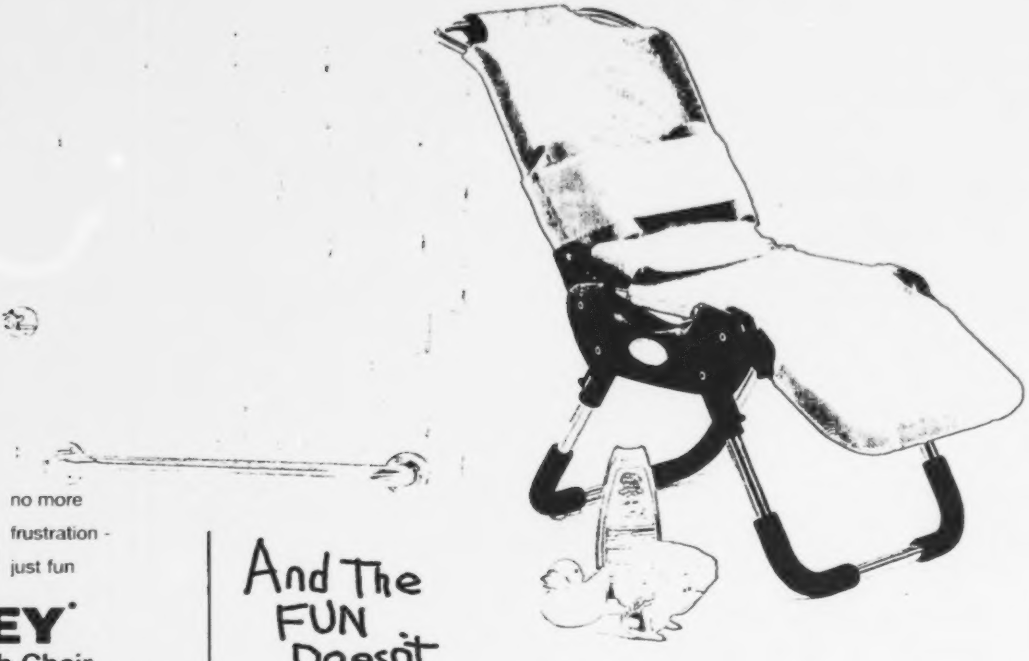
Respond

Baclofen Experiences

A has an eight-year-old boy with spastic CP who has started on oral baclofen in the last year, and she would like to have more information on the treatment.

My daughter is seven years old and has spastic diplegia. She has been on oral baclofen for about a year and a half. Although not dramatic, it does definitely help her. She "scissors" less when she walks, her feet are a little flatter; her fine motor skills (drawing, writing) have made more progress in the last year than they had in five years. Also, she seems to learn new speech sounds more readily, although still hindered by her verbal apraxia (a motor planning problem for speech). The baclofen doesn't make her sleepy, as it does a lot of kids. In fact, it actually makes her just a little

continued on page 24



no more
frustration -
just fun

LECKEY®

Advance Bath Chair

New Design

The most extensive height range and adjustable seat angles make bath positioning easy.

Extra-soft mesh material and padded support bars give your child a more comfortable and enjoyable bath time.

Take the Advance Bath Chair from the tub to the shower with the optional trolley

Also available is the Basic Bath Support that provides adjustable positioning angles at a fixed height.

And The FUN Doesn't Stop There

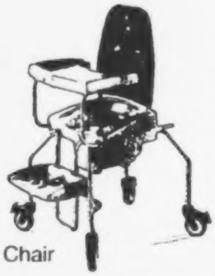
Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Call us today for more information.

- *Lighter mobile bases*
- *More adjustable components*
- *Peer level positioning*
- *Child friendly positioning straps*
- *Playful colors*

Pronestander

Freestander

Totstander



Toilet/Shower Chair

Easy Seat

SAMMONS® PRESTON
an AbilityOne

Leckey® products are brought to you exclusively by Sammons Preston®

Start the fun today! Contact your local Sammons Preston distributor or home health dealer for more information.

Or call Sammons Preston at

1-800-323-5547

Circle #66 or visit www.eparent.com/adinfo

1127

Search & Respond

continued from page 22

hyperactive, and she can't take it in the evening because it affects her sleep and gives her nightmares. Otherwise it doesn't have any side effects for her.

—JB, via EP web site

Botox Injections

A has a nine-year-old daughter who has CP and is going for Botox injections soon.

I have a 10-year-old son with CP. He has had Botox injections in his legs a total of three times, and we have never truly seen any great results. This last set of shots I do not believe benefited him at all. Bottom line: for the cost of the injections, it was not worth the time, nor the crying we put our son through.

—GD via EP web site

Entertaining a Child with Arthrogryposis

CS has a four-year-old daughter with arthrogryposis. She has trouble walking and moving her arms, and she has undergone numerous surgeries. CS would like to hear from other parents with children who face this condition and what they can do to keep their child entertained.

I have a 19-month-old boy who was diagnosed with arthrogryposis. To keep him entertained I usually try musical cartoons and reading to him. I recently bought him an electronic keyboard. Although he can hardly use his hands, he doesn't need to use his fingers to operate this keyboard, instead using his wrist to push the keys or push a rattle lying atop the keys. You also might want to ask your child's therapist about a company called Etech. They make modified toys and they can get you the equipment to modify almost any regular toy

—S via EP web site

Reading Programs for CP Children

A has an eight-year-old daughter with severe CP and is struggling with her reading skills. She would like to know about what kinds of reading programs are available for this population.

I have a seven-year-old daughter with severe CP. She is nonverbal and uses a communication device. I am also a regular education first grade teacher. I felt it was very important that the school get an appropriate reading program for her. She was learning consonant sounds and sight words but there was no consistent program. I did a lot of research and found a program that we are going to use with my daughter this school year. It is by IntelliTools and is called Balanced Literacy. I hope this helps.

—MB via EP web site

PDD/NOS Feedback

A has a nine-year-old son diagnosed with PDD-NOS who is interested in hearing feedback from other parents who have children with this condition.

I have a five-year-old son who has been diagnosed with PDD/NOS. I read two books, *Let me Hear Your Voice* by Catherine Maurice and *Autism & Pervasive Developmental Disorder: A Mother's Story* by Karyn Seroussi. These books give hope to an otherwise hopeless feeling. After reading these books I am a firm believer that some children can and will recover or overcome this disorder. Never give up; keep fighting the good fight.

—M via EP web site

Anxiety and Seizure Control

MH has a five-year-old son diagnosed with mitochondrial encephalomyopathy who was placed on the ketogenic diet last September for seizure control. Though the seizures have subsided, his cognitive and speech skills have regressed and he has developed behavior issues including anxiety. She would like feedback from parents who have been facing a similar situation.

I also have a daughter, now 11 years old, who was once thought to have mitochondrial disease. She started having seizures two years ago and has been on Tegretol since. This year she has begun to manifest stranger anxiety and separation anxiety, which is peculiar since she used to be very social. I have come to believe that my daughter must have had a very negative experience in her school, being maltreated or treated harshly. I wonder if your child's behaviors stem from social interactions, such as having bad experiences with others and then generalizing to her interactions with others, rather than originating from a medical problem.

—R&WB via EP web site

Rights Activist on Residential Placement

TA is looking for parents who have put their children in residential care and she would like to know how to deal with the transition.

I am a disability rights activist. While I believe that people with disabilities should be able to live in the "real world," I recognize that sometimes a residential placement is the best thing for them. Sometimes a child is too medically complicated to live at home, or has behavioral issues that preclude living at home. As a matter of fact, some culturally deaf children decide to go away to a residential school when they are in high school. Just remember that this placement isn't final. Also, recognize that some (normal) kids have to go away to boarding school. You're not putting your kids in the deep dark basement of an institution and forgetting about them. They'll still be involved in life at home. They can come home for weekends and vacations. It's going to be just like they are away at school!

—T via EP web site

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C. & Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #54 or visit www.eparent.com/adinfo

HYPERBARIC OXYGEN THERAPY

Dear Editor,

I'm extremely disappointed in your recent article on hyperbaric oxygen therapy. Citing unpublished data that does not appear to have a control or to be blinded is irresponsible. As you are very well aware cerebral palsy is a developmental disorder that changes over time. The failure to include a control group makes this "study" entirely uninterpretable. Additionally, if there was no blinding the outcomes are also subject to question. Methodologically outcome studies on cerebral palsy are extremely difficult to reproduce. Anyone who has tried to standardize Ashworth sales among a study group can appreciate the great deal of variability that fatigue, mood, pain and hunger can cause.

In my community we have aggressive for profit companies that market hyperbaric oxygen as a miracle cure. I have seen several families give up needed therapies and equipment to pay for this "cure." Within hours of your article endorsing hyperbaric therapy I have received calls crowing your endorsement.

I have enclosed a recent article on hyperbaric therapy that does include a control group and blinding. Please note that both study groups showed improvement with no difference between the study groups. To openly endorse a therapy, on and the basis of unreviewed uncontrolled studies is very disappointing. In my years as a subscriber I have recommended your magazine to all of my patients. If this article is not a momentary lapse, I'll have to reconsider.

Joseph J. Keeley, MD

Dear Dr. Rader,

I have been a regular reader of your magazine. As a pediatrician working in the field of Pediatric Rehabilitation, your publication has often been a good source of information for my clients and their families with respect to community resources, progress and general information about disabilities and healthy lifestyles in general.

I was intrigued to see your "Medical Research Update" article on hyperbaric oxygen therapy. I was, however, distressed to read some of the specific information that you have published, presumably under your editorial review as there was no author cited for this article.

It was with distress that I saw in your second on treating cerebral palsy your comment, "The most widely known is the 'Canadian Study' whose findings are considered interesting but not conclusive due to flaws in the design of the study."

As a practitioner in Canada, I clearly am interested when an individual flags a study in such a manner. I was, however, perturbed to learn that you have dismissed the study because it has some "flaws in the design." From my understanding and reading of the study, it is clear that it was a randomized controlled trial. This is the "gold standard" for evaluation of therapeutic interventions for individuals.

There was no clinical flaw in its design as far as I am able to determine. It was clear that the sham intervention (the use of hyperbaric room air as opposed to hyperbaric oxygen) produced an equivalent effect with individuals with cerebral palsy. If anything, those with room air therapy faired somewhat better.

This is a definitive outcome indicating that hyperaric oxygen is not beneficial for children with cerebral palsy in this situation. Unquestionably, the gold standard of reproducibility of a study over the course of time and in different settings is how we can use the scientific method to ensure veracity of our findings.

I was then more distressed to learn that you are quoting a study between January 1999 and March 2000 done by Evelyn Lipper and Maurine Packard (physicians at Weill Medical College of Cornell University). From your description of this study, it is not a randomized controlled trial. In fact, it is not even double-blinded. Although the researcher used standard assessment tools, you cited the parents' feedback noting changes in their child's progress and regression at the cession of therapy.

This therapy was in no way blinded or evaluated objectively.

You quote the conclusions of the researchers as follows: "For some children with moderate to severe CP, there is evidence that HBOT improves motor skills, attention, language and play…The changes observed do not constitute a cure of CP, but do constitute functionally substantial improvement."

It is only after such an article has gone to and been approved by peer review and then been formally published that these sorts of conclusions can be utilized by the broader medical community. By publishing this in your journal before peer review, you have bypassed this necessary check and balance system. I think that the process that you have undertaken here significantly misrepresents the status of the literature regarding hyperbaric oxygen therapy in children with cerebral palsy.

I would like to see more critical appraisal of the medical literature and review by a practitioner as well as a parent before you publish such things in your magazine. Clearly, this can be misleading when appropriate scientific review process is not applied to the literature that is out there. It is also very clear by just looking at the number of advertisers in your publication that hyperbaric oxygen therapy is obviously a money-making venture. Individuals, who are invested in such therapies as service providers, often do not have the objective point-of-view necessary to critically appraise whether or not such therapy is effective.

Sincerely,
Peter G. Rumney, MD, FRCFC

Dr. Rader replies:

EP doesn't shy away from controversy. The topic might be universal newborn screening for mitochondrial and metabolic disorders or, as in this case, an off-label use of an FDA-approved therapeutic modality. We will present all aspects of the topic in the hope that professionals, parents, families and people with disabilities will absorb the facts and be able to make their own reasoned decisions.

The efficacy of HBOT therapy for people with CP has not been determined. EP's Publisher and I have visited HBOT centers. We have spoken with many parents and caregivers, with physicians and other healthcare professionals, and they have told us of significant improvements that they have seen as a result of HBOT therapy.

We have also spoken with many practitioners who have expressed concerns similar to yours, from the paucity of research on the use of HBOT for CP to the cost of sessions. As the body of knowledge on HBOT for CP grows—whether outcomes are positive, whether improvements are short- or long-term or do not occur at all—EP will continue to cover the therapy. And we also welcome your ongoing response.

A healthy and respectful unfolding dialogue is all EP has ever hoped would emerge from our coverage on HBOT. Perhaps this controversy will eventually be the impetus for the definitive clinical trials on the use of HBOT for neurological deficits, CP and related conditions. Regardless of the outcomes, EP will be proud of its role in serving as a forum for both supporters and critics of HBOT and other controversial but compelling therapies.

"INFORMING, EMPOWERING AND KEEPING PARENTS INVOLVED"

Dear Editor,

Thank you for the excellent series of articles entitled "Informing, Empowering and Keeping Parents Involved". I want to point out an error in the first part, which may mislead parents somewhat. Ms. Gerlach states: "...the Individuals with Disabilities Education Act (IDEA) mandates that children with disabilities be provided with a free and appropriate public education and related services from birth to age 21 years..." However, IDEA only mandates FAPE (a free, appropriate, public education) for children from 3-21. IDEA Part C, the part of the law that provides for Early Intervention services to infants and toddlers from birth to three years old, allows for a system of charges for some services, provided services are not withheld for lack of ability to pay (see Sec. 303.520 of the federal IDEA regulations). These charges cannot circumvent state law, however, so that if a state has a mandate to provide FAPE from birth to 21, that state cannot charge for Early Intervention services. This fee system is also at each state's discretion so that some states may not charge any fees at all, and others will charge for all services that are not free by law. The services that must be provided free of charge to parents/families are:

- implementing the child find requirements;
- evaluation and assessment;
- service coordination; and
- any administrative and coordinative activities related to the development, review, and evaluation of IFSPs and implementation of procedural safeguards.

All other services may incur charges.

This creates great confusion for parents moving from a state which does not charge to a state such as Virginia, which has a sliding fee scale. But parents should be aware that certain charges are allowed by law for Early Intervention services in the birth-to-3 age group.

Sincerely,
Mary Wilt, RN

The editors reply:

Thank you, Ms. Wilt, for clarifying a section on early intervention from Ms. Gerlach's article. As you note, provision of Early Intervention services, and the charges they may incur, do vary from state to state. It would be wise for parents to check the situation in their state at the time their child's initial IFSP is developed.

Panel Members Sought

If you have a child with attention deficit disorder (ADD/ADHD) or are worried that he or she might have it, and would like to participate in a ongoing panel being developed by EP Magazine please email us at epedit@aol.com. Please include "ADD/ADHD Panel" in the subject line. This is not a clinical trial but part of a year-long effort to document and support the efforts of many groups to alleviate the symptoms of ADD/ADHD. Members of the panel will be asked to participate in surveys and discussions about ADD/ADHD. They may also be provided with information about treatments and ongoing research in the field.

We encourage letters on any subject. Send them to: EP Magazine, Attn: Letter to the Editor, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com. Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified by full name and state. Please include your phone number and/or e-mail address on all correspondence.

AN INTERVIEW WITH Francis Collins, MD, PhD, Director of the Human Genome Project

by Lucinda M. O'Neill

As the Director of the National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH), Francis S. Collins, MD, PhD leads the Human Genome Project (HGP), a 15-year, multidisciplinary endeavor to map and sequence all of human DNA. Dr. Collins calls the work of the HGP "the most important organized scientific enterprise that humankind has ever undertaken." A working draft of the human genome sequence was announced by Dr. Collins and the HGP in June 2000 and the completed sequence is expected in the spring of 2003, two years ahead of the projected completion date of 2005. All data uncovered by the HGP have been made immediately available to the scientific community, without restrictions on access or use.

On October 4, Dr. Collins will address the third annual World Conference & Exposition on Disabilities in Orlando, FL, speaking on the medical advances arising from the Human Genome Project and their implications for improving the lives of people with genetic disorders and their families. EP Magazine spoke with Dr. Collins shortly before the conference about the current phase of the project—what he has called the "end of the beginning"—and what lies ahead for genomic medicine. Excerpts from this interview follow.

EP: Dr. Collins, how would you compare the significance of the mapping of the human genome to past medical or scientific milestones?

Dr. Collins: It's an organized scientific effort by a large group of scientists around the world to tackle a very focused and historic set of goals. In that regard, it compares most closely to sending somebody to the moon or to the Manhattan Project to split the atom. But I would argue that this project, in terms of its implications for ourselves, carries even greater weight than those, because it's an adventure into ourselves to understand how we tick. And the implications of that—medically, philosophically and societally—are profound and, I think, outstrip any previous organized scientific effort of any sort.

EP: I understand you're going to be a keynote speaker at the World Congress & Exposition on Disabilities in October.

Dr. Collins: Yes, I am. I'm looking forward to that.

EP: What message of hope do you have to offer the families of people

who have rare genetic disorders for which there is presently no cure?

Dr. Collins: Well, I can say with great certainty that the unraveling of the human genome will lead us to much more detailed insights into the causes of such rare genetic conditions. One can already see that happening: more than 50 genes involved in rare genetic diseases have been discovered in just the last couple of years because of the availability of increasingly better versions of the human genome sequence.

Accurate diagnosis based on detailed molecular understanding of rare genetic disorders will help provide answers to the cause of an illness and the likely course it will follow, and will allow an opportunity to predict more accurately what the risk of recurrence might be. Probably, though, what families are most interested in knowing is how this [information] is going to help with treatment. Ultimately we want to … [be] able to come up with interventions that are more successful than what's currently available. That outcome is going to be unpredictable and each disease will present a different set of challenges. Thus, I would be hesitant to make any sort of global prediction about how quickly therapeutic advances will happen. For some conditions, where the gene turns out to be one that we recognize and have some idea of the role it plays, it may be that an intervention as simple as a dietary change or a drug that's already on the market might provide a light bulb "Aha!" moment. Thus, considerable progress may be achieved for some conditions by the kind of molecular understanding that is going to flow from the genome project.

For other conditions, effective therapeutic interventions are going to be extremely difficult to come up with, particularly if these are conditions that have affected brain development. The idea of being able to fix a condition where there are multiple genes present in too many or too few copies, as in the case of many chromosomal disorders, is difficult to contemplate at the present time.

So I don't want to give people false hope about being able to correct genetic disorders in the near term. At the same time, I think there is reason to be hopeful about some conditions where the revelation of the genetic underpinnings will, over the course of time, lead us to exciting new ideas about what to do.

I know that this news must be hard for parents, families and people with rare genetic disorders who are left in this uncertain state. One thing I can say is that progress in understanding and treating genetic disorders is going to be completely dependent on the best and brightest minds working on the problem and provided with adequate research support.

EP: How will the work that the Human Genome Project is doing now lead to drugs that work better?

Dr. Collins: Certainly we have lots of drugs on the market that work pretty well, but we have a lot that are also somewhat frustrating, where the efficacy is less than it should be and the side effects are worse than they should be. We dream of a new era of genome-based rational drug design where one understands at the most fundamental molecular level what the problem is, and then designs a drug that specifically targets the right pathway, with minimal likelihood of interfering with other processes that would cause unpleasant or dangerous side effects.

I think perhaps this paradigm is most clearly established now for a drug called Gleevec (imatinib mesylate), a treatment for chronic myeloid leukemia. The development of this drug has been a cause of great excitement in the field, not just because it provides a wonderful new therapy for a terrible blood cancer, but also because it establishes the gene-based drug design paradigm in a broader way. What [researchers] did in this particular leukemia was to identify exactly the abnormal protein that is produced in the malignant white blood cells and then figure out its three-dimensional structure. And then they designed a small molecule—a drug—that fits in a lock-and-key fashion into the active site of that particular dangerous protein. It works like a charm. Now nearly everyone with that type of leukemia who is treated with this drug goes into remission.

EP: Well, that's certainly a cause for hope.

Dr. Collins: Indeed. If we can develop that same detailed level of understanding of a particular rare genetic disease, then it might be possible to design a drug that would either block the effect of a protein that is behaving badly or compensate for the absence of a protein that isn't being made. As an example, I'm familiar with what's going on in cystic fibrosis research because I was involved in the discovery of that gene. There are now more than a dozen drugs in clinical trials that are based on the same paradigm of understanding exactly the normal function of a particular protein, and coming up with ways to compensate for it when it's not there.

EP: You've stated that identical twins with identical DNA are also different in pretty significant ways. How do you explain that?

Dr. Collins: Identical twins are a good way of reminding ourselves that DNA is not the whole story about the essence of being human. Twins do indeed have different personalities and behaviors once you get to know them. There's a lot about who we are that is influenced by our upbringing, our school experiences, and our own choices; free will is not going to go out the window just because we've sequenced the human genome. Even more profoundly, I believe there are aspects of who we are as human beings that are more spiritual

continued on page 30

continued from page 29

in nature, and the study of DNA probably won't shed a lot of light on that.

EP: Getting to the major ethical considerations raised by the project, how do you see their impact on people with disabilities or special needs?

Dr. Collins: The genome project is unique in having recognized from the outset that these rapid advances in genetics were going to have significant ethical, legal and social implications (we refer to this as the ELSI program). Rather than waiting for somebody else to deal with those challenges later, HGP decided from the beginning to spend a portion of the budget on researching those issues and proposing possible solutions. This kind of advance preparation has not been done previously in association with an anticipated advance in science.

Issues that might be brought up here would include the genetic discrimination risk. Using genetics to cure terrible diseases is something we'd all celebrate. Using genetics to take away somebody's health insurance or job is profoundly unjust, and ought to be prohibited. Based on research in the ELSI program, a series of detailed policy analyses and strong support from leaders in the executive and legislative branches, we hope to see federal legislation implemented soon that would prevent that kind of genetic discrimination. There are bills in the United States Senate from both parties that propose explicitly how to do this, both for health insurance and for employment.

EP: What's your opinion of universal newborn screening, specifically of tandem mass spectrometry?

Dr. Collins: Newborn screening has been a wonderfully successful program since being introduced some forty years ago, initially for phenylketonuria (PKU). Most states now screen for several different rare conditions. The general criterion for including a condition in the list to be screened is that it has to be something that's treatable and, where treatment is necessary, very early.

Tandem mass spectrometry is an enormously powerful approach, because it allows you in one test to screen for a long list of relatively rare metabolic conditions. But it raises certain concerns, since application of this technology will lead to discovery of some conditions that are not treatable. Even more challenging, there will be occasional discoveries of puzzling findings of unknown significance. A newborn may be detected who is excreting a particular molecule in excess, but with no knowledge of whether that's bad or whether that's just a normal variant. That child and the parents may then be subjected to a lot of investigation and anxiety, trying to figure out what this is, only to discover it's something completely benign.

EP: What does the future hold for genetic counseling, and doesn't such knowledge portend significant responsibility for those professionals acting as counselors?

Dr. Collins: As understanding of the genetic contributions to virtually every condition grows, genetic counseling is going to become even more important than it already is. In fact, the need for this kind of counseling will be so widespread that most healthcare professionals will need to acquire some of those skills. As the genetic contributions to heart disease, cancer, and diabetes are uncovered, many people will want to know their own risk and what they can do about it. Considering the volume of such requests for information, we're going to have to mainstream this kind of individualized preventive medicine. At the same time, genetic counselors are going to be critically needed to handle the more complicated situations where only an expert can sift through the issues. That is particularly likely to be needed for rare conditions, where the average internist or nurse practitioner will not have had enough exposure to that condition to do a credible job of working through the genetic issues with the family.

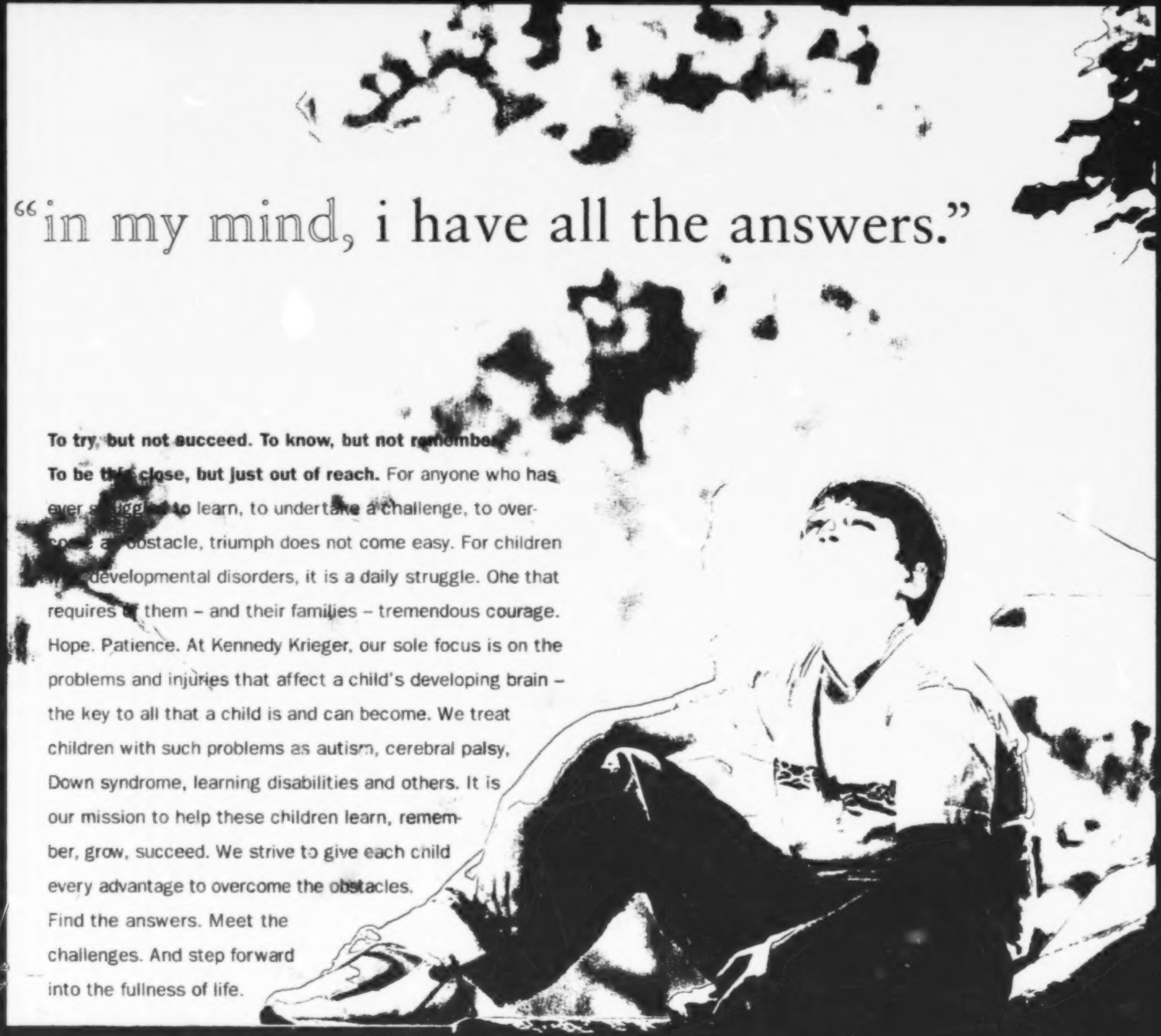
According to Dr. Martin Bax, editor of *Developmental Medicine and Child Neurology*, the human genome project has attracted widespread media attention. However, its benefits may not be directed at many children with disabilities because there are not enough to generate significant profits. He therefore believes that parents will once again need to battle for their children to have effective interventions from this scientific breakthrough.

As he writes, exploitation of the developments will be in the hands of commercial producers. Their main goal will obviously be to make money from the new products that will alleviate the most common conditions. In other words, those individuals with rare conditions will not get the attention they need, as compared to the more common disorders. It will also be difficult for many genetic researchers to keep up with the large volume of findings. Nonetheless, Dr. Bax and everyone else in the disability community welcome the advances made through the genome project.

EP: How are general practitioners going to be trained in genetic medicine over the next 10 or 20 years?

Dr. Collins: That's a big challenge, because in the past most general practitioners have not had meaningful training in genetics. And yet we're talking about them being on the front lines. How is that going to work? Together with the American Medical Association and the American Nurses Association, we've recently founded an organization called

continued on page 32



"in my mind, i have all the answers."

To try, but not succeed. To know, but not remember. To be this close, but just out of reach. For anyone who has ever struggled to learn, to undertake a challenge, to overcome an obstacle, triumph does not come easy. For children [illegible] developmental disorders, it is a daily struggle. One that requires of them – and their families – tremendous courage. Hope. Patience. At Kennedy Krieger, our sole focus is on the problems and injuries that affect a child's developing brain – the key to all that a child is and can become. We treat children with such problems as autism, cerebral palsy, Down syndrome, learning disabilities and others. It is our mission to help these children learn, remember, grow, succeed. We strive to give each child every advantage to overcome the obstacles. Find the answers. Meet the challenges. And step forward into the fullness of life.

Every child is born with great potential.
Shouldn't every child have the chance to achieve it?

BEST COPY AVAILABLE

1/35

Kennedy Krieger Institute
Research. Treatment. Education.

www.kennedykrieger.org Our toll-free referral line: 1.888.554.2080

Circle #48 or visit www.eparent.com/adinfo

continued from page 30

the National Coalition for Health Professional Education in Genetics. It now includes 120 professional organizations that have joined up, representing most of the major specialties and subspecialties in medicine, nursing and other healthcare professions. All of these groups agree that this is an educational challenge that needs to receive high priority. That will mean putting together an educational curriculum for physicians who are already out in practice as well as influencing the curricula for medical students and nursing students so that the next generation is better prepared to deal with this coming revolution. It's going to be a challenge, but the Internet is going to help us a lot here. Probably what will help the most is the fact that patients and families are getting so well informed by using the Internet. If healthcare professionals don't get up to speed on genetics, they're going to discover quickly that the people coming to ask them questions know more than they do, and that's not something they're going to be comfortable with for long.

EP: To what extent will the profit motive guide the development of therapies for genetically-based diseases? For instance, heart disease affects many more people than rare genetic disorders and offers much greater profit potential for drug companies.

Dr. Collins: Well, that is often the way things work in our market-driven economy. Certainly pharmaceutical companies making decisions about where to put their investments in drug development are likely to put them into an area where they think they are going to have a large market. But the Orphan Drug Act can help a lot here. I think there is also a role here for the government. Speaking for the National Human Genome Research Institute, one of the areas that we would like to emphasize is new treatment ideas for rare diseases that might otherwise go unattended. As an example of this emphasis, Dr. William Gahl has just been brought on to direct our intramural clinical program. He is establishing a program that will make it possible for individuals with rare diseases, particularly those in which a diagnosis has not been yet established, to come to the NIH to our Clinical Center for a thorough and detailed evaluation, in order to define the correct diagnosis and determine whether interventions are available.

EP: What's your position on human cloning? Is it ever right?

Dr. Collins: I believe that reproductive human cloning, where the goal is to produce an individual that is a DNA copy of a current individual, has no justification. Such an effort at human cloning would be profoundly unsafe and, in my view, profoundly unethical. I personally hope that we will never see that happen.

The situation is more complicated when it comes to so-called "therapeutic" cloning. Although President [George W.] Bush has clearly stated his opposition to both forms of cloning, here the arguments are less clear, and reasonable people will disagree. There's a potential for major advances against terrible diseases like Parkinson's disease or diabetes or Alzheimer's that sound pretty exciting, although we still don't know whether the promise will be realized. At the same time, I think there are serious ethical concerns about somatic cell nuclear transfer and a question about whether the product of fusion between the nucleus of a skin cell and the cytoplasm of an oocyte should be given the equivalent moral status of an embryo. I think it's unfortunate that those discussions have polarized so rapidly. A lot of the discussion about somatic cell nuclear transfer would be benefited by a more careful understanding of the science. But at the moment, many people seem to have staked out very strong positions on the issue. In my view, it's unfortunate that this has happened so quickly.

EP: What lies ahead for the Human Genome Project?

Dr. Collins: It's wonderfully exciting to stand here on a foundation that has been built over the last 12 years, and be able to see how we can go forward from this to real benefits to health that were unimaginable 20 years ago.

It's going to be very challenging to understand how these three billion letters of our own instruction book operate in health and go awry in disease. It's going to take the best and brightest minds of the scientific community [working] over, probably, decades before we can really say we understand how human biology works. That revelation will come in incremental stages, and some insights will happen more quickly than others. Some dramatic medical applications may happen quickly, and others may be 20 years away.

EP: How would you like to be remembered?

Dr. Collins: That's a hard question. I already feel profoundly fortunate to have been asked to stand at the helm of a project with such remarkable historical significance. I would hope to be remembered as having played that role well, supported by hundreds of creative, hardworking and dedicated scientists. More than that, I would hope that my involvement has moved the possibility of human benefits, particularly the medical benefits, into becoming a reality more rapidly than they otherwise could have. If I've done that, if I've sped up by a day or a week or a year the opportunity to help someone with a serious medical problem, then that would be enough for me. EP

Lucinda M. O'Neill is a freelance writer who lives north of Boston, MA.

Imagine...

all of your other
choices could be this simple

MOTOR COMPANY INC
LIBERTY

Introducing a
zero
maintenance
conversion van with wheelchair access

Starting Under
$20,000 US
(Including vehicle and modification)

- 1996-2002 Windstar Models Available (All vans come with brand new conversions)
- Professionally trained staff ready to help you
- The rear-entry design provides for the safest and most reliable wheelchair accessible minivan on the market.
- The Liberty Motor Co modified Ford Windstar looks and drives like a standard minivan, offering a quiet, comfortable ride.
- Money Back Guarantee

1137

Circle #53 or visit www.eparent.com/adinfo

1 (888) 578-8886 www.libertymotorco.com

Learning Express®

www.learningexpress.com

Your Neighborhood toy store, is pleased to assist Exceptional Parent in their efforts to increase awareness of exceptional children with special needs.

Visit us online at www.learningexpress.com to find a Learning Express store near you.

Your Neighborhood Toy Store

Circle #52 or visit www.eparent.com/adinfo

Toys for all

by Maria Tortoreto

It happens to all kids of all ages:

they see, they want, they ask, and if they're lucky, they get. Maybe their friends have it, maybe they saw it on television, maybe they saw it in the store. Whatever the case may be, in their mind they need to have it. And all too often, after they do get that fabulous new toy, they don't want it.

It's a universal mystery for parents: why do kids not take an interest in that toy that they spend so much money on?

Well, the answer is simple. Kids love toys that they can interact with, try new skills on and test their imagination with. Sometimes even the simplest of toys keep interest the longest. The search for quality, interest-holding toys is always difficult and hard to understand, and usually these toys are found by accident. Children with disabilities, however, have this dilemma tenfold.

Children with disabilities often cannot physically play with a toy as originally designed because they cannot interact with it correctly. They also may not have the mental capacity to understand complicated directions. Parents must always be aware of what their children are interested in and address those interests, but also be aware that if a toy is not appropriate, it is not worth buying.

Paula McSweeney, an early childhood specialist and expert on how kids learn, has a few suggestions for good toys. A good toy must:

◇ have a range of purposes
◇ be relevant to their lives (promote real life situations)
◇ expand the level of play
◇ encompass a range of skills (language, fine motor, cognitive, etc.)
◇ be fun and capture interest

Of course, a toy will not capture interest unless it also has some of the first four qualities.

We don't often realize it, but the best way for children to learn is through playing. Building with blocks helps them develop size and weight concepts, putting on dress-up clothes helps them use small muscle skills and cleaning up toys after themselves helps children accept responsibility.

While many toys are not designed specifically for children with disabilities, parents must be aware of a toy's qualities that would be appropriate for their child. "Disabilities" may have a spectrum of meaning, but some good things to watch out for are big letters, flashing lights, easy- to-hold pieces, etc.

Toys are an integral part of a child's life. Children play all day long, using toys not only as an enjoyable pastime but also as a source of envy among friends. Kids always want what others have, but if what others have isn't practical, then we should help them focus on what is practical for them. Exceptional children may have a modified version of a toy, or something completely different, but that toy may be just as enviable as the rest.

The toys contained in this month's issue have all been used by children with disabilities. While there are many specially-designed toys, our panels of teachers, students and parents recommend these playthings as particularly well suited to children with disabilities.

This year, EP Magazine has chosen to separate them into several categories. The first group represents toys, such as Play-Doh, that are perennial favorites. They are particularly well-suited for kids with disabilities as tools for both motor skills and cognitive growth. (A word of warning: children with pica should be carefully monitored so as not to put the small pieces in their mouths.)

Most of this year's products are new or updated toys chosen because they represent a unique opportunity for children with disabilities. These toys are not "special" or "modified" items but the same products purchased for all children. At the same time, they are safe, challenging and educational.

Also, we have included books, DVDs and videotapes with special appeal or interest to children with special needs.

Finally, as a tip to the future, we are recognizing a truly unique, experimental robot toy that is totally interactive. Developed with the help of government grants, Cosmobot is a robot that mimics the motions of its user. This product is only available in limited situations but is expected to be a popular item in the future.

We welcome nominees for next year's special toys at epedit@aol.com.

continued on page 36

EP Exceptional Achievement AWARD

LINCOLN LOGS

It is hard to imagine that Japan's Imperial Hotel inspired one of America's all-time favorite toys. Yet that is exactly what happened. Lincoln Logs was the brainchild of John Lloyd Wright, whose father Frank Lloyd Wright designed that famous Tokyo building. Fear of earthquakes made the newly created construction technique necessary for the hotel.

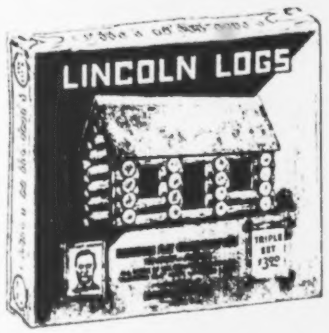
While watching the hotel's special construction techniques, John adapted the system to create Lincoln Logs in 1916. First offered for sale that year, this simple toy building set consisted of miniature hardwood logs notched on the sides to fit into each other. With the toy's elements shaped as unfinished logs, the miniature buildings mimicked the log cabins that were emblematic of American's frontier culture. Thus, Lincoln Logs harken back to a frontier which still existed when John was born. As an educational tool and a tie to pioneer days, they were valued by millions of boys and girls through the 20th century.

John's experimentation with the design of toy construction blocks reflected his own education, which emphasized rhythmic pattern, prefabrication, and construction using interchangeable elements. Lincoln Logs teach spatial relationships, require logic and conceptual thinking, enhance fine motor skills, and encourage creative design and a love of the frontier. In short, they teach and train through play.

For these reasons, EP Magazine has chosen it as the co-winner of the 2002 Exceptional Achievement Award. This award is given annually to a toy or product that has found long-term favor with children and their parents and at the same time provides exceptional educational or training benefits.

Wright's family's values centered in and around "play-full" education. Not only could he see the valuable economic opportunity in the creation of the logs, it was justifiable in terms of fulfilling a very basic and human need—construction. To John, construction meant analytical thought development in children through play; the educational style of his childhood returned him full-circle, to share with the world his practical new toy.

LINCOLN
LOGS
AMERICA'S NATIONAL TOY



The Original Lincoln Logs

The Lincoln Logs in John's original sets came in a much greater variety of sizes than today's version. This compelled children to work out what was to be built through trial and error—forcing them to observe, build, take apart and reassemble.

Historians say the original building sets could be used for the construction of log cabins that were similar to one President Abraham Lincoln lived in as a boy. Later sets became more elaborate and could be used to build forts and other more complex structures. All Lincoln Logs sets contained an instruction booklet; and although the conventional Lincoln Log was round, square logs and even bricks were also sold in the original sets. John even marketed a set called Lincoln Wheels. In 1918, when John coined the phrase "Interesting playthings typifying the spirit of America" to promote Lincoln Logs, it became the slogan for the toy's first advertising campaign.

EP'S ANNUAL TOY SECTION

Developing the toy section every year is a lengthy process. It begins in February, when members of the EP staff attend the toy industry's largest trade show and begin to accumulate information on new toys and games, and ends in early September, when the October issue goes to press. In between, we receive toy samples from the manufacturers and disseminate candidates for coverage to families and schools for their reviews and testing. The EP staff also examines toys we're sent, which means that we also get to play–and comment.

In addition to the new toys, of course, the testers look at some that have been around for years. Through this process, EP Magazine identifies two classic toys for special consideration. This year's toys were nominated and tested almost exclusively by parents and children; some special-ed teachers were included in the panel, too. They told us their favorites, and why they liked them so much. The adult testers were asked to explain to EP Magazine what toys helped children learn new skills, and stretch themselves and grow. Many were nominated via email in response to requests on the EP web site and through the magazine.

Once again, students at the Boulevard School in Ridgefield, NJ were able to play with many of the nominees at school, then take them home for further play. Thus, teachers, parents and kids provided EP Magazine with feedback–commentary, suggestions for improvement, and a sense of how much fun each toy or game engendered. In addition to the testers, we asked other experts on children's development and leaders in the toy industry to give us their suggestions.

In order to qualify for testing, all the toys had to meet a list of criteria developed by EP over the years to keep the children as safe as possible. We required that all the toys must be non-toxic, big

Like his father, John worked as an architect, but unlike his famous parent, lived a rather secluded and private life. Some have speculated that John chose his isolated life because his professional architectural accomplishments seemed slight as compared to the works of his father.

John's Lincoln Logs were an excellent addition' to the building blocks of American childhood, and definitely provided a socially thoughtful approach. It's still a product that is in line with the objectives and environment of their creator. Because they are connected to the widespread nostalgia for the American Frontier, John's Lincoln Logs continue to serve as an educational development tool—one especially useful for children with disabilities.

Play-Doh
CLEAN • NON-TOXIC

PLAY-DOH

If combined, the total amount of Play-Doh compound manufactured since1956 would weigh more than 700 million pounds, equal to the weight of 159 fully-loaded space shuttles. If all the Play-Doh compound made since 1956 was extruded through a two-inch extrusion mold, it would make a "snake" that would wrap around the world nearly 300 times.

Play-Doh's unique ability to entrance, entertain and teach as well as improve spacial coordination has earned it the accolades of parents, healthcare professionals and teachers throughout the world.

For these reasons, EP Magazine has chosen it as the co-winner of the 2002 Exceptional Achievement Award. This award is given annually to a toy or product that has found long-term favor with children and their parents and at the same time provides exceptional educational or training benefits.

Itself a 31-year-old publication, wherever EP Magazine has gone in reporting the real achievements of children and adults with disabilities, Play-Doh has been in evidence as a component of the teaching environment.

As Editor-in-Chief Dr. Rick Rader points out, "Play-Doh acts as a stimulant to the brain and the hands." More than 2 billion cans of Play-Doh compound have been sold since 1956. The toy is approaching its 50th birthday with its popularity almost undiminished since its debut.

Originally, Play-Doh Brand Modeling Compound, a non-toxic reusable modeling compound, was developed and introduced by Rainbow Crafts in Cincinnati. Today it is part of the Kenner toy group. It was first demonstrated and sold in the toy department of Woodward & Lothrop Department Store in Washington,.DC. At the start, Play-Doh compound was available only in one color and size, an off-white, one-pound can.

Next, three new colors were added to the Play-Doh line—yellow, red and blue—and the three-can pack was introduced. Early TV advertising featured Miss Frances on "Ding Dong School" and "Captain Kangaroo." Generations of children have used Play-Doh and their children and grandchildren have been entranced too.

For EP Magazine, the importance of Play-Doh is its ability to help children with disabilities improve their muscle and eye coordination and as a dynamic tool to help them create models of their thoughts. Often, Play-Doh is a method of communication between teacher and pupil; parent and child; physician and patient.

Often immitated but never duplicated, Play-Doh is truly unique—the formula for the original Play-Doh compound still remains top secret.

---

enough not to be swallowed, latex-free, without sharp edges, and sturdy enough to withstand normal play.

A particular quality we look for is a demonstrable benefit from use of the toy. For example, can a child use the toy creatively and with imagination? Does it improve fine-muscle control? Does this toy aid in teaching a child to share?

Given our audience, we try to identify toys that:

- have easy-to-manipulate pieces;
- incorporate vivid and attention getting color;
- feature large type and other visual aids;
- contain elements designed to improve spatial and physical coordination.

Any unusual feature that added to the usability of the toy by a child with disabilities was a plus, and we leaned towards toys that promote active play. For example, a video that draws the child into the action got higher grades than one where the child had only to sit and watch.

As you read and think about these toys and their applicability for your child, it is important to keep a few things in mind.

While EP ensures that all these toys have been selected according to the guidelines noted above, and tested by real people, we cannot guarantee safety, durability, or any other characteristic.

Some manufacturers provide age ranges for their toys based on their use by the child population as a whole. We urge you to use these ranges for comparative purposes only, and to choose items appropriate for your child's level of understanding and physical development.

We welcome your reactions, both positive and negative, and would be delighted to have your own suggestions for toys and games to be tested for next year. Starting in January, 2003, you may nominate toys for next year's issue at epedit@aol.com.

Now, get down on the floor and play!

continued on page 38

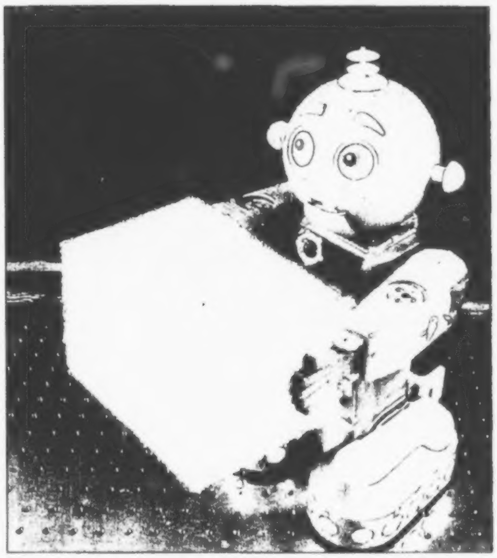
A TOY OF THE FUTURE

Developed as both a clinical tool and a toy, CosmoBot is nearing its debut and is EP Magazine's Toy of the Future for 2002. CosmoBot has the unique ability to: mimic the actions of child operators, react to their actions, and provide visual and oral feedback.

In a clinical setting, CosmoBot is able to record progress during a session without distracting the child. In a home or school environment, it interactively provides children with disabilities an outlet to experience full control and movement.

Equipped with sensors that the child wears on his or her hands or head, Cosmobot mimics both movements and voice. Also, the child or therapist can record a short story with some movements, then play it back.

CosmoBot's control panel has buttons for arm and head movements, all in real time. It can lift, grab, flap up and down and clap. It can also shake its head yes and no. The joystick on the bottom of the control panel allows the child to "drive" CosmoBot. There is also a microphone that allows the child to speak through the robot's mouth. This is great in helping quiet children become more verbal.



AnthroTronix, a leader in development of controlled electronic devices, is creating a clinical and home version. In a clinical setting, special software allows the therapist or parents to record and analyze data over a period of time. Children, engrossed in the interactivity, will not be distracted by notation actions usually associated with a progressive therapy session

AnthroTronix' studies have shown that when the therapist speaks through Cosmobot with the microphone, the child is more apt to listen to instructions. CosmoBot will also contain interactive games, such as Simon Says. For example, CosmoBot can say, "Simon says, say the word yes." The robot contains speech recognition software that deciphers correct and incorrect answers, reacting to the child's response. When Simon asks for an action , with the sensors on, the child performs the action and CosmoBot responds by saying "Good job."

CosmoBot is expected to be commercially available as early as next year. For more information visit www.anthrotronix.com.

2002 TOYS FOR ALL

Baby Cakes Sasha

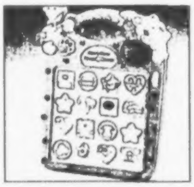
Zapf Creation—$29.99
www.shop.store.yahoo.com
877-629-9273
For ages 3 and up

Baby Cakes Sasha, from Zapf Creations, is an 16-inch upscale play doll. Baby Cakes Sasha sports a pink and white striped romper with matching hat. Under her romper, she is wearing a white long-sleeved cotton shirt with elastic at the wrists and sleeves trimmed with pink. This adorable toy is sure to be a nice addition to your family of dolls.

Ben Bear

The Ben Bear Company, LLC—
$15.99- $19.99
www.BenBearCollection.com
847-496-4087
For ages 5-12

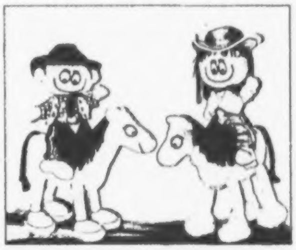
Ben Bears are available in seven colors and four fur options, to encourage collecting. Each bear features a signature denim bow tie and embroidered foot pad indicating Ben's city of origin or "place of birth." Ben Bears and their varied "home towns" help children develop a love and excitement for travel and geography at a young age.



Blue's Clues Press and Guess

Fisher-Price—$12.99
www.fisherprice.com
800-432-5437
For ages 3 and up

The Blue's Clues Press and Guess toys develop reasoning and memory skills. With Press and Guess Snacks, Joe, the host, gives kids clues to help them find the snack he's looking for, or he will test kids' memories by asking them to repeat a sequence of icons. With Press and Guess Music, Joe gives kids clues to help them find the instrument he's looking for. Kids can also press a series of musical instruments and then hear back the sequence they created.



Born to Ride

Playground Enterprises—$11.95
www.puzzlezoo.com
818-503-0161
For ages 2 and up

This toy features Danny or Sally riding a horse and is an imaginative product that is designed for play in the Wild, Wild West. The dolls and horses are all flexible enough for posing.

All prices are suggested retail costs as supplied by the manufacturers.

Bright Buddies

Darmos Toys–
$2.99 to $4.99
www.darmos.com
800-327-6674
For ages 9-14

These flashlight keychains are available in eight realistic animal styles: alligators, dolphins, whales, tigers, elephants, frogs, sharks and chimpanzees. Key chains can help children remember which backpack belongs to them or be a friendly reminder of where they put something. The mouth must be pulled open for the keychain to light, preserving battery life, and tough plastic makes the toy durable.

Call 'n Learn Video Phone

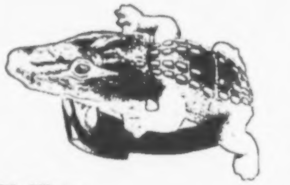
Vtech Int.–$4.99
www.mailorderexpress.com/vtechshop.html
312-297-7512
For ages 3 and up

Call 'n Learn Video Phone uses voice activation technology to help young talkers learn early phone role-play skills. The phone rings to "call" children and then responds to their voice with role-play questions. Activities reinforce community helper roles–doctor, police officer and firefighter–counting skills, safety tips and music. This phone has many realistic features such as a dial tone, working headset, light-up speed dial and even voicemail.

Cariboo

Cranium, Inc.–
$16.94
206-652-9708
For ages 3- 6
www.playcranium.com

Find castles, boats, and balloons, while exploring a golden island in Cariboo, the treasure hunting game. As kids look for bounty on the island of Cariboo, they have fun taking turns unlocking secrets, matching pictures and other activities while developing important skills with letters, numbers, colors and more.



Digitime

Darmos toys–$3.99 to $4.99
www.darmos.com
800-327-6674
For ages 3 and up

This creative spin-on watch provides kids with more than just the time. Each watch is built as one of seven cool animals that tell the date and time, and the back of every watch has information on its animal. Available styles are alligators, dolphins, elephants, lizards, monkeys, sharks and tigers.

Dizzy Disc Jr.

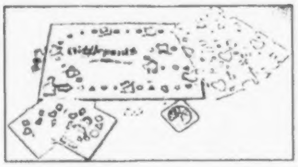
Quantum Toys–
$69.95
www.quantumtoys.com
info@quantumtoys.com
For ages 5 and up

The Dizzy Disc, Jr. has a 16-inch surface that allows for standing, sitting or kneeling. With this toy, children can hone fine motor skills and sense of balance. There is also a built-in level to adjust the difficulty of the angle.

Geosafari World Globe

Educational Insights–$59.95
www.educationalinsights.com
800-933-3277
For ages 8 and up

This unique globe offers over 5,000 geography questions that test a child's "geo-IQ". Its features include an updated world map and an easy-to-use interactive database stand. This globe provides children with hours of educational game-play.



GIGGLEPANTS™

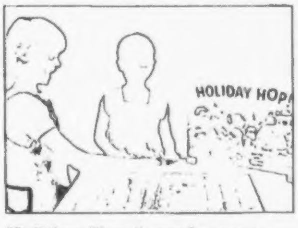
Games For All Reasons, LLC–$22.95
www.game-board.com
781-648-2029
For ages 3-5
Designed for two to four players.

Children move pawns around a board in an effort to collect six different-colored shapes. When the child lands on a shape, he or she places a cutout of that shape onto his or her own card. The first player to fill the card with all six shapes is the winner. The Gigglepants are play pants which players can put on if they land on the Gigglepants space, a character instead of a shape.

Gwigglerz

Damos Toys–$9.99 to $12.99
www.damos.com
800-327-6674
For ages 3 and up

Gwigglerz resurrect the Slinky in brightly colored animal forms such as elephants and geckos, whales and sharks, snakes and alligators. Plastic springs provide the mid-bodies for these vibrantly colorful, three-dimensional creations that can be walked on their "leashes" making them wiggle and slide. Gwigglerz are soft, springy and cute, and each has its own distinct personality that allows a child to create stories.

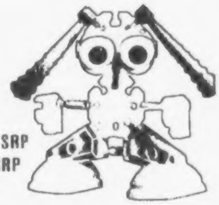


Holiday Hop board game

Liberty Games–$21.99
www.libertygamesinc.com
518-899-6559
For ages 5-12

Holiday Hop is a fast-paced game of history, facts and holidays through the calendar year. Your child will enjoy the twists and turns of this colorful game as the positions on the board change rapidly. Get to New Year's Eve and win the game! Learn well-known holidays, historical people, famous inventions and fun days, while learning color, picture matching, sequential numbering, days of the month and months of the year.

KID K'NEX™



K'NEX®–
from $9.99 SRP
to $19.99 SRP
www.toys-rus.com-
available November 2002
212-465-1290
For ages 3-7

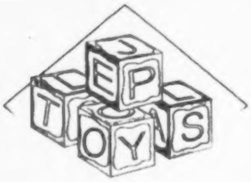
Young builders can make new friends with KID K'NEX building sets. Large chunky parts, crazy colors and big buggy eyes go together easily and are great for young minds and small hands. Each set includes plenty of KID K'NEX rods and connectors plus special feature parts and a fun picture book filled with great building ideas. KID K'NEX™ develops creativity and fine motor skills.

Hide and Seek Plush

On a Lark/Imagination Project–
$12.00
www.toyclassics.com
888.477.6532
For ages 18 months to 7 years

Talking cats play the traditional hide-and-seek game. Place the cat in its hiding place and activate the voice by pressing its paw. The cat will then repeat "I'm over here!" every 30 seconds until it's found. Once the cat is found and picked up the cat says, "You found me! Give me a big hug! Let's play hide and seek again!" After that, it's time to find a new hiding place and play again.

continued on page 40

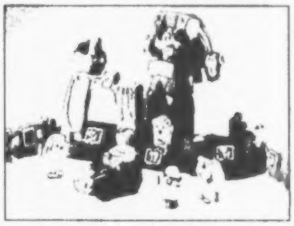


Little Doctor Kit

Little Doctor Kit

International Playthings–$18.99
www.intplay.com
info@intplay.com
For ages 2 and up

The Little Doctor Kit has an electronic stethoscope that makes a heartbeat and coughing sound. The blood pressure gauge with arm cuff includes a pump with a spinning dial. The set also includes a doctor bag, reflex hammer, thermometer, squeaking syringe, auriscope, laryngoscope and pretend bandage. The stethoscope includes 3 button cell batteries.



LITTLE PEOPLE® ANIMAL SOUNDS ZOO

Fisher-Price–$19.99
www.fisherprice.com
800-432-5437
For ages 1-5

Toddlers will learn all about the different animals that live at the zoo and discover the different sounds they make. This interactive playset comes with six animals including an elephant, polar bear, lion, seal, monkey and a bird, plus a zoo keeper, food basket, vehicle and two connecting fences to extend play out and around the zoo.

Maggie Raggies Sweetie Singer

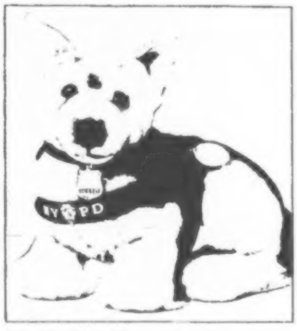
Zapf Creation AG- $29.99
www.zapf-creation.com
877-629-9273
For ages 3 and up

Maggie Raggie Sweetie Singer is 18" long with a flexible frame, plush body, soft hair, Velcro hands for holding accessories, playful facial expressions and a wire skeleton for posing and standing. Children will be able to bring her to life by pressing on her belly and listening to her sing– the harder her tummy is pressed, the louder she will sing.

NameTrains

Maple Landmark–$4.75-$52.75
www.vtwood.com
800-421-4223
For ages 3 and up

NameTrains are simple enough for a young child to enjoy and diverse enough with accessories, blocks and track to keep older children engaged and entertained. Each train car is in the shape of a letter; they come in six different non-toxic vibrant colors. Each letter stands about 2.5 inches high and 3 inches long. They connect with simple magnets and are compatible with other wooden track systems and most related accessories. Solid construction of New England rock maple, easy-roll wheels and strong magnets gives the letters durability.



NYPD Plush

Applause, LLC–$8.00 to $25.00
www.applause.com
800-777-6990
For all ages

Kids can play with these soft plush dolls from the NYPD and Applause toys. The dolls include a rendition of Apollo from the city's K-9 Unit as well as a number of the horses from the Mounted Unit line.

POWER PUMPER

Columbia-Inland Corporation–$150
www.powerpumper.com
888-215-7867
For ages 5-11

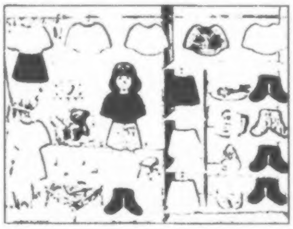
This innovative, award-winning design moves by a unique push-pull rowing motion of a pumper bar that also steers the ride-on toy. The Power Pumper 2000 is an Industrial Design Excellence Award (IDEA) winner and has been named the world's safest ride-on.. With its full body play, children can have fun while getting the exercise they need.

Roll With It, Baby! Roller

Imagiix Milestones–$14.95
www.babyscholars.com
800-462-4449
For infants ages 6-12 months

The Roll With It, Baby! roller is a plastic cylinder that inflates to 16"x 9" and is covered with a colorful, soft, machine-washable cloth. The soft fabric cover has a fun theme featuring a dog, cat, mouse and cheese. Each end contains two jingling bells for added enjoyment. Made for infants, the Roll With It, Baby! roller can help introduce a baby to rolling, balancing and pushing.

TEXTURED DRESS -UP PUZZLE



Lights, Camera, Interaction!– around $14.99
www.inquisitoy.com
800-284-3948
For ages 3 and up

The Textured Dress-Up Puzzle has 18 interchangeable dress-up puzzle pieces in a variety of bright, colorful patterns and materials. Carved wooden pieces make moving and manipulating the outfits easy, while the various textures (silky, plush, patterned, shiny, etc.) can be mixed and matched to create beautiful outfits and build on the child's sensory awareness and vocabulary skills. This classic-style wooden puzzle includes 7 blouses, 6 skirts and 5 pairs of shoes.

Toy section compiled and written by Arnold Kim

continued on page 42

WHY CHILDREN WHO RELY ON GOODNITES ARE MORE INDEPENDENT.

Independence means different things to different people. For children with bladder or bowel control problems, it could just mean getting through the day dry. That's why something as simple as a change in clothing can, even in a small way, change a child's way of life.

GoodNites® absorbent underpants can help a child become more independent. With GoodNites, accidents won't become catastrophes. So your child will be able to do more. Plus, because they look like real underwear, kids don't mind wearing them. And since they're easy to pull on and off, they can make a child feel more self-reliant.

GoodNites are available in 3 sizes: 45–65 lbs., 65–85 lbs., and 85–125 lbs. That means finding the size that fits your child will no longer be a problem. Plus, they have tear-away sides and they're latex-free.

- *Day and nighttime protection*
- *Latex-free*
- *Tear-away sides for easy removal*
- *Three sizes, to fit kids from 45–125 lbs.*

Imagine your child gaining a little more independence just from a change in clothing. For information on how GoodNites can help, please visit us at www.goodnites.com/sn.

Pull-Ups
GoodNites
DISPOSABLE ABSORBENT UNDERPANTS
45 lb & over

For Better Days

®Registered trademark of Kimberly-Clark Corporation. ©2002 KCC

Circle #50 or visit www.eparent.com/adinfo

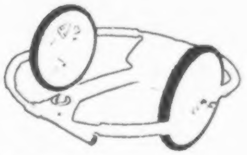
EP TOYS

U.S. Dogs
U. S. Dogs—$48.00
www.us-dogs.com
888-270-4460
For ages 8 and up

U.S. Dogs offers plush stuffed dogs that come with accessories, board books, and a mission to give children a better understanding of pet ownership. Each dog is designed to move in hundreds of poses to encourage role-play and fun.

Walk-A-Pets
Darmos toys—$3.99
www.darmos.com
800-327-6674
For ages 3 and up

The simplicity of these toys allows children to create their own stories and expand their imaginations. They are available in multiple lines including aquatic, zoo, farmyard, marsh, canine, science and technolgy.



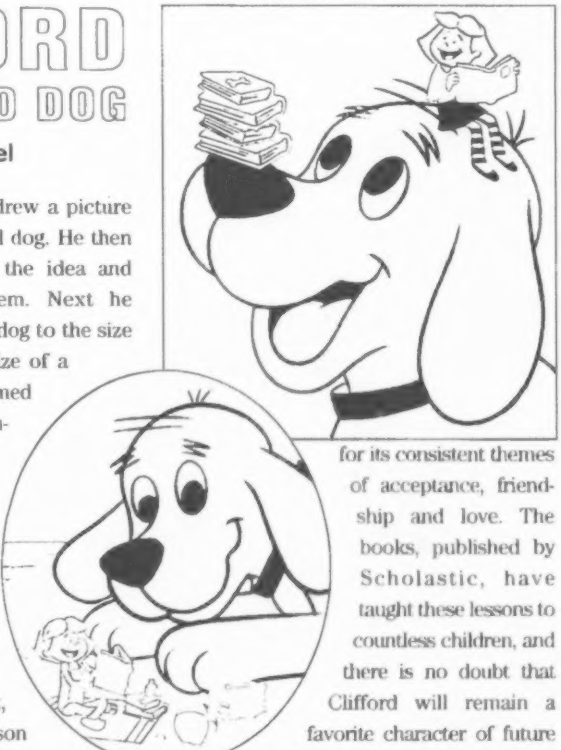
Whirly Wheels
Quantum Toys—$59.95
www.quantumtoys.com
info@quantumtoys.com
For ages 3-7

Whirly Wheels is a low-to-ground ride-on toy that provides fitness for young riders. Children rotate the handles of one or both wheels to turn, spin in a circle or go straight. With this toy, children can strengthen their arms and chest and improve coordination. A fun way for kids to have fun while staying in shape.

MEDIA REVIEW

CLIFFORD
THE BIG RED DOG

by Laura Apel



In 1962, Norman Bridwell drew a picture of a little girl with a big red dog. He then decided to continue with the idea and wrote a story about them. Next he enlarged the picture of the dog to the size of a horse, and then the size of a house. Bridwell's wife named the dog Clifford and the couple named the little girl Emily Elizabeth, after their own daughter. Forty years and nearly 100 million books in-print later, Clifford The Big Red Dog is celebrating his anniversary with a special edition of the book, and going into the third season of his award-winning, number one rated PBS KIDS television show. Nevertheless, regardless of all his achievements, Clifford simply remains the big red dog that two generations of kids have fallen in love with.

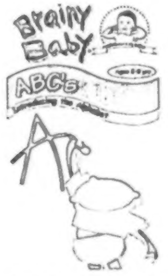
EP Magazine has chosen to recognize Clifford The Big Red Dog as a classic among literature for children throughout the world for its consistent themes of acceptance, friendship and love. The books, published by Scholastic, have taught these lessons to countless children, and there is no doubt that Clifford will remain a favorite character of future kids everywhere.

Everyone remembers reading about Clifford. The red dog who grew to the size of a house when he was still only a puppy has captured the hearts of children and parents alike since his first book was published. His size got him into trouble time and time again as he always seemed incapable of controlling his large and awkward body. Like other dogs, Clifford sometimes chased cars or dug up flowers, but his mistakes and messes were always far greater with much worse consequences.

For this reason, children with disabilities may find themselves relating to the red dog in ways that are unique to them and their feelings, fears and struggles. Throughout the stories of Clifford's many adventures and mishaps, he is teased and ridiculed for his size, color and clumsiness. Children learn from Clifford's experiences that although they may be different, that does not mean that they are not special and worth being friends with. Clifford always manages to overcome the obstacles that come before him, and in the end he has the support of those who know and love him.

On this 40th anniversary of our friend Clifford, EP Magazine would like to thank Norman Bridwell and his lovable character Clifford and praise them for standing out in children's literature as a series that has employed valuable themes that will continue to resonate with future generations of child readers everywhere.

For more information on where to find Clifford The Big Red Dog books and memorabilia and for information on the hit television show, please visit www.scholastic.com.



Brainy Baby ABCs video

Brainy Baby company—$15.95
www.brainybaby.com
800-664-4594
For ages 2-5

With this video, a child is introduced to the alphabet. Upper and lower-case letters are taught, as well as multiple letter-sounds. It is a comprehensive and entertaining video that can aid in learning letters.

First Impressions
Letters

First Impressions "Letters" video

Small Fry Productions—$15.95
www.small-fry.com
800-521-5311
For ages 1-5

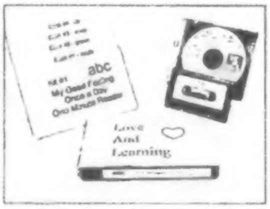
Prepare your child for the alphabet with First Impressions "Letters", a video that will enhance your child's desire to learn through fun-filled exercises. The video develops early-learning skills by associating letters with familiar objects, animals, toys and children. With the help of friendly voices and happy music, the video will introduce your child to the wonderful world of the ABCs.

First Impressions
Shapes

First Impressions "Shapes" video

Small Fry Productions—$15.95
www.small-fry.com
800-521-5311 • For ages 1-5

This video shows your child the fascinating world of shapes. Through several fun-filled exercises, your child can learn to find his/her way around basic everyday shapes from squares to circles to triangles.



Love and Learning Videotapes

Love and Learning—$63
www.loveandlearning.com
313-581-8436
For ages 6 months and up

With the Love and Learning kits, your child can be introduced to reading at a very fast pace. There are three parts to each learning kit. An audiotape works on vocalization and is played at naptime, bedtime or playtime and lets the child hear the words spoken in a clear, slow manner. A videotape repeats the same words visually and phonetically, again in a clear, focused presentation. Special books clearly present the same letters/words and, when used for just a few minutes each day, provide a special time for parent and child to read together.

Read-Along
DVD
Story Songs
Vocabulary
Learn in 5 Languages
Monsters, Inc.

Monsters, Inc. Read-Along DVD

Walt Disney Records—$14.95
www.amazon.com
800-237-5751
For ages 2-6

The movie story comes to life on screen with words and pictures featuring word-for-word narration and original character voices. Learn vocabulary from the movie in five different languages: English, German, French, Italian and Spanish. DVD includes story, sing-along songs, interactive game and the video "Making of Monsters, Inc. Scream Factory Favorites."

Signing Time!

Signing Time. Volume I: My First Signs VHS

Two Little Hands Productions—$14.95
www.signingtime.com
801-571-2445
For ages 0-5

From their magical animated world, Alex (who can hear) and Leah (who is deaf) invite infants and children to "come sign with us." Watch and enjoy as Alex, Leah, and their friends of varying ages illustrate American Sign Language (ASL) in a fun and playful way. This thirty-minute video explores eighteen child-friendly signs and exposes kids to many more through two original songs.

Team Xtreme

Pathways Development Group, Ltd.—$349.00
www.pathwaysdg.com
877-742-4604

Team Xtreme is a video game interface that adapts Nintendo, NES, Super NES and N64 game systems for people with disabilities. This new adaptation is not just for fun. The skills encouraged through its use allow people to learn how to use switches, work on hand-eye coordination, motor skills and mental and physical endurance. The interface also allows children to build new friendships while playing with peers, whether or not they have special needs. Models for games released in 2002 are also being prepared by the company.

Created by Mike Andrews, the unit meets the strict standards set by Nintendo and has numerous safety features including latex-free casing and overlay links, very low leakage currents on switch inputs and protection against static damage. According to the manufacturer, green and yellow lights are used instead of flashing red lights to help avoid possible seizure inducements.

continued on page 44

TOP TEXTS FOR TOTS AND FUN FOR THE KIDS...

FishTales: Rabbit Fish's Ears

By Larry Stern and Stu Krieger
EP Library Code: 1RL8309YP
Price: Not Available

Billy is always upset about his red hair because it makes him different. One night he dreams of an aquatic world inhabited by Dogfish, Giraffefish and Rabbitfish, among others. When Rabbitfish runs away because he thinks his ears make him different, Billy learns that physical features aren't what matters, it's what's inside that counts.

Education: ☆ ☆ ☆ ☆ Entertainment: ☆ ☆ ☆ ☆

Never Give Up and Go For It!

By Andy Andrews
EP Library Code:DPL100XYP
Price:$13.00 (four titles)

This series provides a compilation of letters from multiple heroes to help young people learn never to give up and always "Go For It!" Different volumes tell the stories of American, sports, inspirational and celebrity heroes. Also provided are guided activities that help children figure out who their own heroes are.

Education: ☆ ☆ ☆ ☆ Entertainment: ☆ ☆ ☆ ☆

Let's Start Finger-Painting

EP Library Code: SD4675YP
Price: $12.95

This activity book provides eight tubes of finger paint and all the accessories needed to create a masterpiece. Easy step-by-step instructions are provided in this durable hardback book, as well as sample pages that make projects easier to complete.

Education: ☆ ☆ ☆ Entertainment: ☆ ☆ ☆ ☆

Social Skills Story Books

By Cindy A. Bailey
EP Library Codes::
Doctor: DR6643YP
Grocery Store: DR66XYP
Dentist: DR6651YP
Price: $3.95 each

These compact, lightweight board books provide children with practical information and pictures of real people that explain good behavior during family outings. Available titles include *Going to the Doctor*, *Going to the Grocery Store* and *Going to the Dentist*. Each book provides explanations of what parents will be doing and what children can do to help.

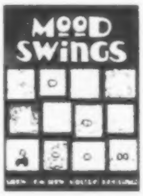
Education: ☆ ☆ ☆ ☆ Entertainment: ☆ ☆

Bobby Bear

EP Library Code: SD8344YP
Price:$12.95

Bobby Bear's day is the subject of this durable board book. Each page brings an experience with a new animal, and involves the child in a counting or sensory exercise. Thick pages and simple text make this book an easy way to have fun and learn.

Education: ☆ ☆ ☆ Entertainment: ☆ ☆ ☆ ☆



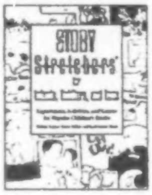
Mood Swings

EP Library Code: PSS5606YP
Price:$7.99

Drawn by cartoonist Jim Borgman, this book provides children a chance to communicate and an opportunity to learn. Pictures with facial expression help children learn about different feelings.

Education: ☆ ☆ ☆ Entertainment: ☆ ☆ ☆

FOR THE PARENTS...



Story Stretchers for Infants, Toddlers and Twos

By Shirley Raines, Karen miller and Leah Curry-Rood
EP Library Code: GH2744YP
Price:$19.95

A "story stretcher" is a teaching concept that works directly with the ideas presented in a specific book. This resource gives information on specific books, and then provides 3 or 4 "stretchers". All information is organized by book and accompanied by material lists and simple diagrams.

Education: ☆ ☆ ☆ ☆ Entertainment: ☆ ☆ ☆ ☆

Playing to Learn

By Carol Seefeldt
EP Library Code:GH2639YP
Price:$19.95

This new book details fun and simple activities that help children develop learning skills. Chapters explain activities for every occurrence in a child's life. It consists of simple illustrations and a section of recommended aids to parental understanding.

Education: ☆ ☆ ☆ ☆ Entertainment: ☆ ☆ ☆

EP'S EXCEPTIONAL EVALUATIONS:

☆ ☆ ☆ ☆ Stars : Exceptionally Beneficial
☆ ☆ ☆ Stars: Very Beneficial
☆ ☆ Stars: Beneficial
☆ Star: Somewhat Helpful

EP'S TOY LADY

by Maria Tortoreto

Donna Caroccia is a lucky lady. She goes to work with a smile on her face every day, and leaves without ever changing expressions. But then again, how can she not smile when her job is to play with toys and children all day?

As EP Magazine's official "Toy Lady," Donna gives us new ideas and we in turn give her new toys for her preschool classes. For the past ten years, she has been a preschool teacher for disabled students at the Bergen Boulevard School in Ridgefield, New Jersey, where the curriculum consists solely of playing with toys.

"The children learn by playing," she explains. "It teaches them new skills and how to cooperate."

Donna came to EP Magazine about five years ago in search of new ideas for her classes, and we gave her an assignment: to be our "Toy Lady." As companies send us samples of new toys which could possibly be appropriate for children with disabilities, we give them to her to test out with the children. After all, children themselves are the best testers of toys!

Donna and her students have become a routine part of our magazine production for the October "toy issue" of EP. All year long, Donna collects the toys and sends them home for a few days with each child along with a survey for the parent to fill out. She then makes a list and returns it to us, giving us ideas for good toy nominations and allowing us to respond to the companies that send toys to us.

As a mother of two daughters, now ages 20 and 17, Donna was able to study typical child development when they were growing up. Using that as a guide, she knows where children should be in various stages and distributes toys to her preschoolers appropriately.

Donna is certified in special-needs teaching for grades K-8, and has a master's degree as a learning disabilities teacher-consultant. Donna has been helping young children to grow and expand their horizons for years, and as she moves on next year to second-through-sixth grade classes, she will take her passion with her.

For more information on these and other fun books contact the EP Library online (http://www.eplibrary.com), by fax (201-947-9376) or by calling (800) 535-1910.

She's Got The *Beat*

By Jennifer Kirby & Lori Ostrover

Star Anthony, her husband Larry Greenstein and their two sons Kevin and Thomas.

When Dr. Star Anthony and her husband, Larry Greenstein, welcomed their new baby boy Kevin into the world ten years ago, they didn't know that a new career for Anthony would be born as well. Interactive Metronome (IM), a computer-based training program that uses sound as a means of improving one's timing, is now being used as therapy for people with disabilities. Anthony has been an IM trainer since February of 2001.

Kevin was born with mild cerebral palsy, fine and gross oral motor issues and a visual disability, Anthony explains. "We knew right away that he was going to have issues, so we began seeking out appropriate treatment for him at an early age."

At first, they enrolled their then-eight-month-old in an early intervention program, but soon discovered it was not addressing his needs. Determined to find a treatment program that would, Anthony and her husband began investigating several early childhood development programs near their Port

continued on page 46

What is Interactive Metronome? The process includes the use of a set of headphones and computer software, along with hand- and foot-sensing triggers. One sensor consists of Velcro wrapped around the hand, and the other is a flat pad on which the foot can tap. Both devices have sensors inside which click, then send messages to the computer.

The user first undergoes a long form test. Under the guidance of an IM trainer, they listen for the beat produced by the IM computer software. After hearing it, they must anticipate the next beat by tapping one of the sensing triggers. Meanwhile, the IM program measures how much ahead or behind the user is to that beat in milliseconds. The closer someone is to the beat, the better their timing and the lower their score. By examining the milliseconds read by the computer, the IM provider is then able to design an appropriate program for that individual so they may improve their timing.

The program typically consists of 15 one-hour sessions over a three- to five-week period. Short tones can be added to the original beat to tell the user how far ahead or behind they are from the original beat, which sounds a bit like a cow bell. This helps users to accurately correct their timing. According to IM inventor/senior vice president, research and product development, Jim Cassily, the program can also be used by those with hearing impairments because the beat's vibrations can be felt through the headphones.

It is important to note that IM is not a cure, but a learning enhancement tool. It is for those children and adults who have attention and/or motor control/coordination problems, learning disabilities, traumatic brain injuries, cerebral vascular injuries (stroke), Parkinson's disease or autistic spectrum disorder.

BEST COPY AVAILABLE

The History OF IM

When musician/record producer Jim Cassily had his own recording studio in Ann Arbor, Michigan during the 1960s and 70s, he noticed that some musicians had natural timing, while others did not. "We call it the 'cook,'" he explains.

Although Cassily had used traditional metronomes—a pendulum-like instrument used to help musicians keep a steady tempo by listening to a click—he realized that in order to teach cook he'd have to make it interactive for two reasons. First, the regular metronome doesn't let you know if you're ahead or behind the beat. Second, the instrument acts as an anchor, because when musicians play with a person or group, they have a tendency not to listen or work with the other tempos.

In 1993, Cassily used a large box, complete with a built-in dedicated computer processor, and several pieces of professional audio processing equipment to create an interactive metronome. He began training several musicians. By chance, a doctor asked Cassily to try this new process on his friend, who had been in a car accident that resulted in brain injury. Cassily's additional background in child psychology made him eager to try it on children who had a variety of special needs, and did this with the help of Easter Seals. One of his first students was an eight-year-old named Jimmy Eggleston.

The young boy was born with no right leg, dislocated hips, no ligaments in his left knee, severe scoliosis and a diaphragmatic hernia which kept his lungs from fully developing. He also had a trache and oxygen tank and was unable to swallow whole food for the first five years of his life. "My wife is a pediatrician and had taken piano herself for a few years. She knew of the developmental value of music training and we both observed Jimmy's interest in music, so we thought lessons would be good for him," explains Jimmy's dad, Tom.

And so in the summer of 1994, before Jimmy was to enter the second grade, Cassily began working with him. By the third session, Tom and his wife Kathy began noticing a change—Jimmy's balance seemed to be improving. By the fifteenth session, Jimmy was able to walk without his walker. They also saw improvements in his piano playing, coloring, handwriting and attentional problems.

Soon after, Cassily met a child with autism, with whom he wanted to begin IM Training, though that child had been seeing Dr. Stanley Greenspan on a bi-annual basis for several years, so his mother wanted to make sure it was all right with Dr. Greenspan before proceeding. Greenspan gave his okay and by the next time he saw the boy, which was in 1995, he was so pleased with the results that he immediately got in touch with Cassily, who asked him to come on board as the Chairman of IM's Scientific Advisory Committee.

Although the interactive metronome Cassily had originally envisioned became available in 1999, it has only recently become a focus of the media and special needs community. A published study on "The Effects of Interactive Metronome Training on Children With ADHD," which appeared in the March/April 2001 edition of The Amercian Journal of Occupational Therapy, has given a big boost to the product's credibility. It proved that timing is an important component for planning, sequencing and focusing, and that these things are indeed relative to attentional problems.

Tom Eggleston became impressed with this therapy, and wanted to get more involved. In January of 2001, he resigned as senior vice-president of e-commerce for AutoNation, Inc., a billion dollar company, to become IM's CEO. "I have a real passion that this tool can touch and reach the lives of children as it has our own son," he says.

Today, IM is used in over 600 clinics, schools and hospitals. Eggleston hopes that network continues to grow, particularly in the realm of geriatrics, where he hopes IM will help elderly people regain their functioning. Dr. Greenspan, who retains his private practice in Bethesda, Maryland, sees continuing ambitious research as part of the future. Currently, studies are being done on Parkinson's disease, as well as unexceptional students and professionals.

continued from page 45

Washington, Long Island home. Subsequent to speaking with several of these program's directors, one director in particular suggested they get in touch with renowned child psychiatrist and author, Dr. Stanley Greenspan.

Greenspan currently has a practice in Bethesda, Maryland, where he works with a wide range of children. The 30-year medical veteran developed an interest in children who have special needs at the National Institutes for Mental Health.

Anthony and her husband became very impressed with Greenspan after reading his books and reviewing his credentials. They immediately set up an appointment for Kevin, and eight years later they still depend on him for guidance when it comes to their ten-year-old son.

Last spring, Greenspan suggested that Anthony and her husband should treat their son's physical, occupational and speech therapy difficulties, to name a few, through IM. Anthony and her husband immediately began looking into it, and learned why it was successful in helping to develop attentional and motor skills.

Timing May Really Be Everything

Recent research (particularly the study on "The Effect of Interactive Metronome Training on Children With ADHD," published in the March/April 2001 issue of The American Journal of Occupational Therapy) has shown that timing is a very important component of human development. It affects the ability to plan and sequence actions, which are both related to cognitive and physical achievement.

Greenspan explains, "Timing affects many areas of learning: the ability to write an essay, tie your shoes, sequence your ideas and

BEST COPY AVAILABLE

socialize. These things all require some sequencing and planning." By exercising one's capacity for rhythmicity and timing, planning and sequencing improve and progress can be made in academics, motor skills and more.

It is important to note that IM is not a cure, but a learning enhancement tool. It is for those children and adults who have attention and/or motor control/coordination problems, learning disabilities, traumatic brain injuries, cerebral vascular injuries (stroke), Parkinson's disease or autistic spectrum disorder.

Becoming an IM Trainer

Anthony and her husband did their research, came across a trainer on IM's web site, and took Kevin in for his

continued on page 48

Jim Casslly, the inve[illegible] of IM, demonstrating how the program works.

Do you or someone you know have ADHD?

If you or someone you know experiences one or more of the following challenges often displayed by those who have ADHD, you may be interested in a breakthrough technology program called Interactive Metronome® (IM).

__ **Poor Coordination**

__ **Difficulty with language processing**

__ **Aggressive behavior**

__ **Difficulty focusing/concentrating**

__ **Difficulty with reading fluency**

Findings from a double blind, placebo controlled study on subjects diagnosed with ADHD showed those who completed the IM program saw improvements in attention, coordination, control of aggression, reading and language processing. This study was peer reviewed and published in the *American Journal of Occupational Therapy*.

Interactive Metronome is a non-invasive software program proven to produce significant gains in all of the above areas in just 3-5 weeks. This innovative technology program is available through your local health-care provider. To find an IM provider in your area, log onto **www.interactivemetronome.com** .

interactive metronome

Circle #47 or visit www.eparent.com/adinfo

continued from page 47

initial assessment. The service provider wasn't sure exactly how much pre-training Kevin would need since his scores were outside the program's starting point. Anthony soon decided she wanted to be Kevin's trainer herself.

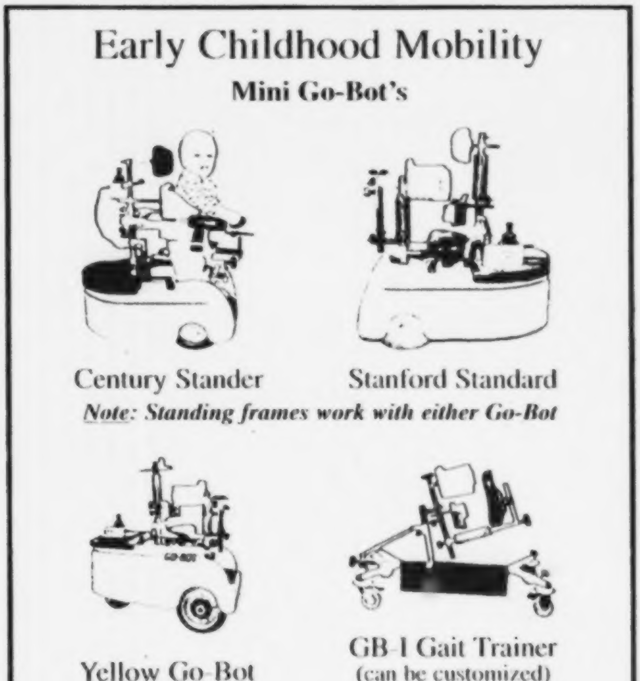
There are different kinds of IM service providers, and IM has strict provider qualifications in the area of healthcare. Once your credentials are deemed appropriate and you've undergone the essential training program, you can then order the package for $2700. Anthony was able to become an IM healthcare provider due to her 12-year background as a chiropractor, and she now holds the title of Clinical IM Trainer. For non-healthcare-related applications, a professional background is not required.

Anthony confesses, "Kevin is still in pre-training, but it's getting there. People at technical support and people I met at a recent IM conference have given me ideas on how to adapt the exercises to his special needs." For instance, because of his balancing difficulties, he often does the exercise lying down. Anthony's IM practice seems to be evolving.

Fellow Port Washington resident Andrea Scharf decided to put son Jamie, a classmate of Kevin's, into IM training with Anthony after the two spoke about it. "Jamie is classified as learning disabled. He's been receiving speech therapy since he was 17 months old and occupational therapy at about 26 months old, and he still receives both in school," Scharf explains. "We started his training in April of 2002 and he had more than 15 sessions, because he needed two or three pre-training sessions. I think [IM] definitely helped. With academics, there was less frustration and breaking down and while Jamie has always been a strong reader, I noticed an increase in his concentration on what he was reading." In addition, Scharf has also seen an increase in her son's gross motor skills on the baseball diamond.

Noting improvements Anthony sees in kids like Jamie inspires her to move away from her chiropractic vocation and concentrate more on her IM training. She claims, "A lot of these kids are not used to succeeding in things, but they gain a great deal of self-confidence through doing this because it is hard and challenging. You're learning something new and you're working hard at it and that's why I love it."

For more information on Interactive Metronome, visit their web site at http://www.interactivemetronome.com.


Early Childhood Mobility
Mini Go-Bot's
Century Stander
Stanford Standard
Note: Standing frames work with either Go-Bot
Yellow Go-Bot
GB-I Gait Trainer
(can be customized)
Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com
Circle #46 or visit www.eparent.com/adinfo

MIDWEST MOBILITY & DESIGN INC
ACCESSIBLE TRANSPORTATION
Drop Floor Minivans
Sport Pickups
4" x 6" Drop Floors
Raised Roofs & Doorways
- Rental Vans
- In Stock Units
- New & Used
- Ship Anywhere
- Financing
- Trade-ins

WWW.MIDWESTMOBILITY.COM
1-800-809-3738
NATIONWIDE
1-847-923-9892
CHICAGOLAND AREA
Since 1972
An All Star Distributor of Braun Mobility Products
★★★★★
5 Star Dealership
Circle #59 or visit www.eparent.com/adinfo

The Center for DISCOVERY

The Center for Discovery is certified by New York State through the State Education Department, the Department of Health and the Office of Mental Retardation and Developmental Disabilities (OMRDD); and by the Commission on Accreditation of Rehabilitation Facilities (carf).

Visit us at Booth #730 at The World Congress & Exposition on Disabilities in Orlando, Florida — October 3-5, 2002

Please read the four-part series, "Transitions: Informing, Empowering and Keeping Parents Involved," (June through September) currently appearing in Exceptional Parent Magazine.

Don't miss the special presentation, "Transitions: Informing, Empowering and Keeping Parents Involved," at the WCD (Oct. 4, at 2:00 p.m.) that will address the issues raised in the four-part EP series.

Be sure to attend the presentation at the WCD (Oct. 3, at 3-5 p.m.) highlighting the outcomes of The Center for Discovery's International Summit, entitled "Disabilities: Sharing Visions for the Future" that was held at The Center this past June.

The Center for Discovery, a nationally-renowned prep school for children with significant disabilities (including multiple disabilities, medical frailties and some behavioral concerns) recently opened several new, small, universally-designed residences.

Located near Monticello, NY in the picturesque Catskill Mountains, just two hours northwest of New York City, The Center features a nature-based program that challenges children, and their families, to work with us to provide the finest educational, clinical, social and residential opportunities available anywhere.

We may just be
the right program
for your child.

Call our Admissions Office at (845) 794-1400, extension 1444 for information and/or to arrange a personal tour and see *discovery* in action.

Ask for our new video.

Box 840 / Harris, NY 12742
845-794-1400, extension 1444
email: admiss@sdtc.org

Visit our websites:
www.thecenterfordiscovery.org
www.discoveryifi.org

BEST COPY AVAILABLE

Circle #71 or visit www.eparent.com/adinfo

PRACTICE PARAMETER: Screening and diagnosis of autism

Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society

EP Magazine will be exploring the causes, effects and treatment of autism through 2003. As a basis for planning these articles, and to invite comment and contributions, we are publishing the "Practice parameter: Screening and diagnosis of autism" from the report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society.

Level one: routine developmental surveillance and screening specifically for autism.

Analysis of the evidence. **When and how often should developmental surveillance/screening be performed?** Approximately 25% of children in any primary care practice show developmental issues. However, fewer than 30% of primary care providers conduct standardized screening tests at well-child appointments. The American Academy of Pediatrics (AAP) stresses the importance of a flexible, continual developmental surveillance process at each well-child visit, and recommends eliciting and valuing parental concerns, probing regarding age-appropriate skills in each developmental domain, and observing each child.

What are the appropriate developmental screening questionnaires that provide sensitive and specific information? Developmental screening tools have been formulated based on screening of large populations of children with standardized test items. Sensitive and specific developmental screening instruments include: the Ages and Stages Questionnaire, the BRIGANCE Screens, the Child Development Inventories and the Parents' Evaluations of Developmental Status.

The Denver-II (DDST-II, formerly the Denver Developmental Screening Test-Revised) has been the traditional tool used for developmental screening, but research has found that it is insensitive and lacks specificity. The Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ) was designed to identify a subset of children who needed further screening. However, studies have shown that it detected only 30% of children with language impairments and 50% of children with mental retardation.

How are conventional developmental milestones defined? Conventional developmental language milestones are based on normative data from numerous standardized language instruments for infants. Lack of acquisition of the following milestones within known accepted and established ranges is considered abnormal: no babbling by 12 months, no gesturing (e.g., pointing, waving bye-bye) by 12 months; no single words by 16 months; no 2-word spontaneous (not just echolalic) phrases by 24 months; and any loss of language or social skills at any age. Failure to meet these milestones is associated with a high probability of a developmental disability.

Do parents provide reliable infor-

mation regarding their child's development? Several studies encompassing 737 children showed that parental concerns about speech and language development, behavior, or other developmental issues were highly sensitive (i.e., 75% to 83%) and specific (79% to 81%) in detecting global development deficits. However, the absence of such concerns had modest specificity in detecting normal development (47%). An additional study that combined parental concern with a standardized parental report found this to be effective for early behavioral and developmental screening in the primary care setting.

Can autism be reliably diagnosed before 36 months of age? Because there are no biological markers for autism, screening must focus on behavior. Recent studies comparing 109 autistic and 33 typically developing children demonstrated that problems with eye contact, orienting to one's name, joint attention, pretend play, imitation, nonverbal communication, and language development are measurable by 18 months of age. These symptoms are stable in children from toddler age through preschool age. Retrospective analysis of home videotapes has also identified behaviors that distinguish infants with autism from other developmental disabilities as early as 8 months of age.

Current screening methods may not identify children with milder variants of autism, those without mental retardation or language delay, such as verbal individuals with high-functioning autism and Asperger's disorder, or older children, adolescents, and young adults.

Is there an increased risk of having another child with autism (recurrence)? The incidence of autism in the general population is 0.2%, but the risk of having a second (or additional) autistic child increases almost 50-fold to approximately 10 to 20%.

What tools are available with appropriate psychometric properties to specifically screen for autism? Appropriately sensitive and specific autism screening tools for infants and toddlers have only recently been developed, and this continues to be the current focus of many research centers. The Checklist for Autism in Toddlers (CHAT) for 18-month-old infants, and the Autism Screening Questionnaire for children 4 years of age and older, have been validated on large populations of children. However, it should be noted that the CHAT is less sensitive to milder symptoms of autism, as children later diagnosed with PDD-NOS, Asperger's, or atypical autism did not routinely fail the CHAT at 18 months.

The Pervasive Developmental Disorders Screening Test-II (PDDST-II) for infants from birth to 3 years of age, the Modified Checklist for Autism in Toddlers (M-CHAT) for infants at 2 years of age, and the Australian Scale for Asperger's syndrome for older verbal children, are currently under development or validation phases.

What screening laboratory investigations are available for developmental delay, with or without suspicion of autism? *Formal audiologic evaluation.* The Committee on Infant Hearing of the American Speech-Language-Hearing Association developed guidelines for the audiologic assessment of children from birth through 36 months of age. They recommended that all children with developmental delays, particularly those with delays in social and language development, have a formal audiologic hearing evaluation. Three studies have documented that conductive, sensorineural, or mixed hearing loss can co-occur with autism, and that some children with autism may be incorrectly thought to have peripheral hearing loss. In addition, transient conductive hearing loss associated with otitis media with effusion can also occur in children with autism.

Audiologic assessment of such children requires modifications of traditional test techniques and environments (e.g., operant test procedures). Electrophysiologic procedures are useful for estimating hearing sensitivity and for examining middle ear, cochlear, and VIIIth nerve or auditory brainstem pathway integrity. Evoked otoacoustic emissions are useful for examining cochlear (sensory) function, and is a frequency-specific, as well as a time-and cost-efficient procedure. Frequency-specific auditory brainstem response (ABR) is the single most useful electrophysiologic procedure for use in estimating hearing thresholds, and has been demonstrated to be highly correlated with behavioral hearing thresholds in children who hear normally and in children who have sensorineural hearing loss.

Lead screening. Children with developmental delays who spend an extended period in the oral-motor stage of play (where everything "goes into their mouths") are at increased risk for lead toxicity, especially in certain environments. The prevalence of pica in this group can result in high rates of substantial or recurrent exposure to lead. The National Center for Environmental Health of the Centers for Disease Control and Prevention recommends that children with developmental delays, even without frank pica, should be screened for lead poisoning. Blood levels in children with autism are elevated . In one study, the mean blood lead level in 18 autistic children was higher than in 16 nonautistic "psychotic" children or in 10 normal siblings; 44% of the autistic and psychotic children had lead levels significantly above the mean compared with control subjects. In a more recent study, 17 autistic children treated for lead poisoning were compared with 30 children without

continued on page 52

continued from page 51

autism. The autistic children were older at diagnosis, had higher lead levels, and most were reexposed despite close monitoring of their environment.

Level two: diagnosis

and evaluation of autism. *Analysis of the evidence.* **Who should diagnose autism?** Although educators, parents, and other health care professionals identify signs and symptoms characteristic of autism, a clinician experienced in the diagnosis and treatment of autism is usually necessary for accurate and appropriate diagnosis. Clinicians must rely on their clinical judgment, aided by guides to diagnosis, such as DSM-IV and the Tenth Edition of the International Classification of Diseases (ICD-10), as well as by the results of various assessment instruments, rating scales, and checklists. These instruments and criteria should be used by practitioners not as experienced in the diagnosis of autism.

What are the medical and neurologic concerns in evaluating children with autism? *Family prevalence.* Family studies have shown that there is a 50-fold to 100-fold increase in the rate of autism in first-degree relatives of autistic children. Within these families, there are also elevated rates of social difficulties; higher incidences of cognitive, communication, learning and executive function deficits; increased stereotyped behaviors; and anxiety, affective, language, and pragmatic disorders. Monozygotic twin pair studies have also shown a high concordance rate (60%) for DSM-IV Autistic Disorder, 71% for the broader autistic spectrum phenotype, and 92% for an even broader phenotype of social and communication deficits with stereotyped behaviors that nonetheless were clearly differentiated from normal. In contrast, no concordance for autism was noted in dizygotic twin pairs and only 10% were concordant for some form of cognitive, social, or language deficit.

Large head circumference without frank neuropathology. Children with autism have a larger head circumference; only a small proportion have frank macrocephaly. Large head size may not necessarily be present at birth, but may appear in early to mid-childhood, perhaps indicating an increased rate of brain growth. Neuroimaging studies in autism also found larger brain volumes without associated neuropathology.

Association with tuberous sclerosis complex (TSC) and less often with Fragile X (FraX) syndrome. Seventeen to over 60% of mentally retarded individuals with TSC are also autistic, and these patients commonly have epilepsy. In contrast, the number of autistic individuals with TSC has been estimated to be between 0.4% and 3%. This rate increases to 8% to 14% if epilepsy is also present.

Clinical studies report that 3% to 25% of patients with FraX have autism. However, no evidence of FraX in autistic individuals was found using cytogenetic (not DNA analysis) techniques; with molecular genetic analyses, only a few autistic individuals were shown to have FraX.

What are the specific deficits of the autistic child's developmental profile? *Speech, language, and verbal and nonverbal communication.* Verbal and nonverbal communication deficits seen in autism are far more complex than simple speech delay, but overlap with developmental language disorders or specific language impairments. Expressive language function ranges from complete mutism (as often seen in children 2 to 3 years of age) to verbal fluency, though verbal abilities are often accompanied by many errors in word meaning (semantics) or language and communicative deficits in social contexts (social-pragmatics).

Cognitive deficits. Many autistic individuals demonstrate a particular pattern on intellectual tests that is characteristic of autism, i.e., performance IQ (PIQ) higher than verbal IQ (VIQ), and specific intersubtest scatter, with Block Design typically the highest subtest and Comprehension usually the lowest. However, the PIQ-VIQ split is severity dependent. When Full Scale IQ (FSIQ) and VIQ are both above 70, 80% of autistic individuals will have no significant VIQ-PIQ disparity, and the remainder are evenly divided between those with PIQ > VIQ and those with PIQ < VIQ.

The DSM-IV defines the diagnosis of mental retardation as the combination of subaverage intellectual functioning (IQ> 70) and concurrent deficits in adaptive functioning. Autistic individuals have poorer adaptive function than would be predicted by IQ alone.

Sensorimotor deficits. Impairments of gross and fine motor function are reported as being common in autistic individuals, and are recognized as hypotonia, limb apraxia, or motor stereotypies. Motor deficits are more severe in individuals with lower IQ scores. Hand or finger mannerisms, body rocking, or unusual posturing are reported in 37% to 95% of individuals, and often manifest during the preschool years. Sensory processing abilities are aberrant in 42% to 88% of autistic individuals and include preoccupation with sensory features of objects, over- or under-responsiveness to environmental stimuli, or paradoxical responses to sensory stimuli.

Neuropsychological, behavioral, and academic impairments. Specific neuropsychological impairments can be identified, even in young children with autism, that correlate with the severity of autistic symptoms. Performance on tasks that rely on rote, mechanical, or perceptual processes are typically spared; deficient performance exists on tasks requiring higher-order conceptual processes, reasoning, interpretation, integration, or abstraction. Dissociations between simple and complex processing are reported in the areas of language, memory, executive function, motor function, reading, mathematics, and perspective-taking. There is no reported evidence that confirms or excludes a diagnosis of autism based on these cognitive patterns alone.

When and what laboratory investigations are indicated for the diagnosis of autism? *Genetic testing.* A chromosomal abnormality reported in possibly more than 1% of autistic individuals involves the proximal long arm of chromosome 15 (15q11-q13), which is a greater frequency than other currently identifiable chromosomal disorders. Those with the 15q abnormalities typically have moderate to profound mental retardation. The duplication is usually maternally inherited, either pseudodicentric 15 (inverted duplication 15) or other atypical marker chromosomes, with one or two extra copies of the area roughly corresponding to the typical Angelman syndrome (AS)/Prader Willi syndrome (PWS) deletion region of approximately four million base pairs. Conversely, AS is usually due to a deletion of maternally inherited 15q11-q13 material and has been found in patients with autism and profound mental retardation.

Metabolic testing. Inborn errors in amino acid, carbohydrate, purine, peptide, and mitochondrial metabolism, as well as toxicologic studies, have been studied, but the percentage of children with autism who have a metabolic disorder is probably less (and some experts agree that it is considerably less) than 5%

Electrophysiologic testing. The prevalence of epilepsy in autistic children has been estimated at 7 to 14%, whereas the cumulative prevalence by adult-

continued on page 54

Worth the work

Autism doesn't diminish Jack's need to assert his independence, but it does create some obstacles. At Heartspring we provide him with a picture schedule in the home and classroom settings to give each day a predictable structure. It's working remarkably well for everyone involved; Jack gets to enjoy an enhanced sense of self-worth ... we get to see that great smile.

HEARTSPRING™
SCHOOL
Finding New Ways for Learning
8700 East 29th Street North · Wichita, Kansas 67226
call 1-800-835-1043
www.heartspring.org

Circle #22 or visit www.eparent.com/adinfo

1157

continued from page 53

hood is estimated at 20% to 35%. Seizure onset peaks in early childhood and again in adolescence. Mental retardation, with or without motor abnormalities and family history of epilepsy, was a significant risk factor for the development of seizures in autistic individuals.

It is unclear whether there is a relationship between autism and an early regressive course (before 36 months), childhood disintegrative disorder ([CDD] after 36 months), Landau-Kleffner syndrome, and electrical status epilepticus during slow wave sleep (ESES). Autism with regression and CDD have both been associated with seizures or epileptiform sleep-deprived EEG (with adequate sampling of slow wave sleep). A higher incidence of epileptiform EEG abnormalities in autistic children with a history of regression has been reported when compared to autistic children with clinical epilepsy. Seizures or epileptiform discharges were more prevalent in children with regression who demonstrated cognitive deficits. Regression in cognition and language in adolescence associated with seizure onset has also been observed, but little is known about its cause or prevalence. There may be a causal relationship between a subgroup of children with autistic regression and EEG-defined "benign focal epilepsies." There is insufficient evidence to suggest a role for event-related potentials or magnetoencephalography in the evaluation of autism.

Neuroimaging. CT studies, ordered as standard assessments of children diagnosed with autism during the 1970s and 1980s, reported a wide range of brain imaging abnormalities and suggested that there was an underlying structural disorder in patients with autism. This view changed when Damasio et al. demonstrated that such abnormalities were incidental to coexisting anatomic disorders unrelated to autism. A very low prevalence of focal lesions or other structural abnormalities was found; their inconsistent localization marked them as coincidental. Prevalence of lesions on MRI in children with autism is similar to normal control subjects. CT and MRI studies of autistic subjects screened to exclude those with disorders other than autism confirmed the absence of significant structural brain abnormalities.

Functional imaging modalities such as functional MRI (fMRI), single-photon emission CT (SPECT), or positron-emission tomography (PET) are currently only research tools in the evaluation of autism. There is no evidence to support a role for functional neuroimaging studies in the clinical diagnosis of autism at the present time.

Other tests. There is insufficient evidence to support the use of other tests such as hair analysis for trace elements, celiac antibodies, allergy testing (particularly food allergies for gluten, casein, candida, and other molds), immunologic or neurochemical abnormalities, micronutrients such as vitamin levels, intestinal permeability studies, stool analysis, urinary peptides, mitochondrial disorders (including lactate and pyruvate), thyroid function tests, or erythrocyte glutathione peroxidase studies.

P.A. Filipek, MD; P.J. Accardo, MD; S. Ashwal, MD; G.T. Baranek, PhD, OTR/L; E.H. Cook, Jr., MD; G. Dawson, PhD; B. Gordon, MD, PhD; J.S. Gravel, PhD; C.P. Johnson, MEd, MD; R.J. Kallen, MD; S.E. Levy, MD; N.J. Minshew, MD; S.Ozonoff, PhD; B.M. Prizant, PhD, CCC-SLP; I.Rapin, MD; S.J. Rogers, PhD; W.L. Stone, PhD; S.W. Teplin, MD; R.F. Tuchman, MD; and F.R. Volkmar, MD

HDIS

Convenient Home Delivery of Bladder Control Products

Try Tranquility® All-Through-the-Night Disposable Briefs, FREE!

FREE Sample Offer!

More absorbency means more comfort and protection.

- Extraordinary absorption capacity.
- No need for multiple changes through the night.
- Latex-free construction.
- Wide range of sizes (including youth) to assure a comfortable fit.

Call now for your FREE sample!

1-800-2MY-HOME®

(1-800-269-4663)

"We're happy to answer any questions you might have."

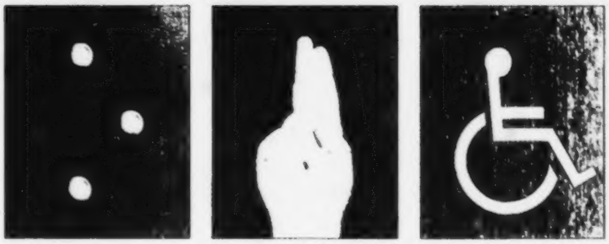
- Mary

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

©2002, HDIS 024-134

Circle #41 or visit www.eparent.com/adinfo

©2002 Merrill Lynch & Co., Inc.



Be open. Because some visionaries are blind. Because some communicators are deaf. Because some movers and shakers are paralyzed. Because the only true disability is a mind stuck in the closed position. Be bullish.

ml.com

Merrill Lynch

Circle #58 or visit www.eparent.com/adinfo

Summarizing Alternative Treatments
FOR AUTISM AND OTHER DEVELOPMENTAL DISORDERS

By Laura Apel

The search for effective treatments can be difficult and exhausting for parents whose children suffer from autism and other developmental disorders. Successful, non-drug approaches that many parents may not realize can be among their options are examined by Dr. Lewis Mehl-Madrona. Throughout this report, "Alternative and Innovative Therapies for Developmental Disorders," which is available on line at http://www.eparent.com, the importance of basic and enjoyable acts of love, attention and enthusiastic high expectations is stressed.

Many observers believe drug therapies do not significantly improve the condition of the child, which has left parents searching elsewhere for any answer to what can be done to help. Dr. Mehl-Madrona has spent a great deal of time and research on providing these parents with possible answers to their dilemma and his report furnishes readers with a plethora of information.

As a preface to his list of possible alternative methods Dr. Mehl-Madrona explains that there has not yet been definitive evidence to support any single cause of autism, and that because of this no exact cure has been produced. However, he began his research and compilation after parents of children with autism brought several factors to his attention.

They included the observation that children with developmental disorders could be accessed through astonishingly simple actions such as:

- being paid attention to;
- being cared for;
- being massaged;
- being placed on special diets.

From this, he deduced that it was possible for these children to eventually become indistinguishable from those who did not have the disorder.

The therapies that Mehl-Madrona recommends range from simple behavioral changes such as increased enthusiasm and a higher level of expectations by parents and doctors regarding the child's potential, to more complex dietary approaches including a gluten/casein free diet that requires an elimination of all grains, soy and dairy from the child's meals. This particular dietary change as a treatment is based on the theory that autism might be caused by an elevated level of opiates, which are present in gluten/casein proteins. Most parents are simply not aware that something as common as the removal of milk from their child's everyday diet could eventually prove beneficial to improving their symptoms.

Dr. Mehl-Madrona also discusses the role that metabolic abnormalities have in autism, and the effect that nutritional therapies may play in the improvement of a child's condition. Once metabolic consequences of an enzyme defect are recognized and defined, the child's symptoms can be treated with specific dietary changes, drugs and/or nutritional supplements.

The author goes into great detail about the reasons for and benefits of particular vitamins and then recommends a basic supplement program including, "vitamin C, trace minerals (vanadium, germanium, selenium, tungsten, tin, etc.), common minerals (zinc, manganese, magnesium, calcium), B vitamins (with extra thiamin, B6, and B12), vitamin A, evening primrose oil, marine lipids, OPC-3's and vitamin E."

Also discussed in depth are the effects that environmental toxins, such as pesticides and herbicides, may have on genetically vulnerable individuals with autism. The suggestion is made that early exposure to synthetic chemicals, coupled with impaired liver detoxification, could be responsible for the increase in the incidence of autism that has recently developed.

Related to this theory is the impaired sulfate metabolism theory of autism, in which the impairment of the acid affects the detoxification process, causing degenerative neurological and immunological conditions. Environmentally acquired mercury is also thought to be a possible cause of autism based on the idea that it causes immune, sensory, neurological, motor and behavioral dysfunctions that are commonly associated with autism. This form of mercury can be contracted from vaccinations or simple casual contact. As treatment, Dr. Mehl -Madrona suggests the application of chelating agents to remove the toxic agents.

Environmentally acquired mercury is also thought to be a possible cause of autism based on the idea that it causes immune, sensory, neurological, motor and behavioral dysfunctions that are commonly associated with autism.

The hormone secretin is also proposed as an alternative therapy where dramatic improvement has been documented in some children who have received specific doses. Treatment of children with autism with anti-viral therapy can be beneficial when used to treat the signs of long term or chronic viral infection.

Children with autism may have defects in their immunity, so Dr. Mehl- Madrona also addresses the subject of immunotherapy, and the treatment with intravenous immunoglobulin G. Children with chronic viral infections and other immune deficiencies have are believed by some to benefit from the therapy where Vitamin C, oligoprocyanidins and anti-inflammatory fatty acids are also mentioned as possible cohabitants against the condition.

Homeopathy is a controversial treatment used in the treatment of the signs of autism, but one that Dr. Mehl-Madrona has found effective in his personal experience. In this approach small amounts of toxic substances are used in an attempt to stimulate the body to heal from these substances. Dietary modifications are recommended in order to facilitate the release of toxins, such as alkanizing agents like spinach, cucumber, carrot, beets and celery, and avoiding tomatoes, red meats and other acidic foods.

Another approach discussed is the effect of body therapy and manipulative therapies on children with autism A recent study compared children who received 15-minute massages prior to bedtime and children who were read Dr. Seuss stories by their parents at bedtime. Members of the massage therapy group exhibited less stereotypical behavior and more on task and social relatedness behavior during observations at school.

Craniosacral therapy, where the bones of the skull and the spine are adjusted, and chiropractic manipulation are also mentioned as having positive outcomes. In addition, the simple and rewarding act of holding a child with autism is reported to improve social interaction and responsiveness.

Sensory integration therapy, in which the child receives multiple, simultaneous stimuli from different sensory modalities in an attempt to harmonize these miscellaneous inputs, is also discussed. Simultaneous communication and multisensory input aimed at alleviating the children's difficulties in information processing, organization of experience, and affect is also examined, but results in this area are preliminary at best.

The report concludes with a discussion of three forms of psychological and behavior therapies used in the treatment of children with autism.

The first is the technique of adult imitative behavior as an early intervention.

Next is the use of music as a therapy, which has been shown to have an easing and therapeutic effect with some children.

Finally, naturalistic behavior therapy, in which the child is taught specific skills through interaction in particular trials where the correct response is rewarded, is discussed. The key aspect of this approach, as described by Dr. Mehl-Madrona, is that the child should be placed in natural situations where there will be the opportunity to be rewarded for what he or she already enjoys taking part in.

Doctor Mehl- Madrona addresses notes that, although drug therapies can be helpful, his intent is to present to parents who are dissatisfied with medications, alternative therapies that can aid in the treatment of a child with autism Throughout the discussion of the many methods that can be utilized, the report repeatedly emphasizes the simplicity involved in some basic and effective fundamentals of childcare, that may be trivialized by even the most informed of parents. EP

Off-Label Use of Pharmaceuticals

By Julia Steele

Once the Food and Drug Administration (FDA) has approved a given drug as safe for one use, physicians are free to prescribe it for any condition. This is called "off-label" drug use, because drugs are being used for purposes other than those indicated in their labeling information (also called prescribing information or PI).

The reasons for growing off-label use are many.

Sometimes Doctor X will notice that a patient—or two or three or more—who has been prescribed a particular drug as treatment for condition A will also show improvement in condition B. The doctor might then prescribe the same drug to treat condition B only. If it seems to work, Doctor X will tell a few colleagues, who will then try the therapy. Information about positive outcomes might be the basis for a poster session at a major medical meeting and, thus, widely disseminated.

In treatment of cancer and other terminal illnesses, as much as 60 percent of the medication prescribed is off-label. Physicians want to help their patients, or at least ameliorate symptoms; the patients feel they have nothing to lose; and so they are both willing to try any treatment that might help. Also, because there are so many types of cancer, a drug approved for one cancer might be used off-label to treat another type of malignancy. For instance, use of a drug approved for one form of lung cancer to treat liver cancer is considered off-label.

In pediatrics, drugs are prescribed to treat the conditions for which they are approved in adults, but are classified as off-label because they have not been approved for use in children. Many drugs lack approval for kids simply because there is a shortage of children for clinical trials, perhaps because the parents don't know that a trial is underway for which their child might be eligible.. Children are not miniature adults; effective dosages are based on several factors besides height and weight. Thus a drug could be perfectly safe for minors, but without sufficient data the FDA will not approve a pediatric indication. In the past few years a program has been in place in which drugs tested and approved for pediatric indications are granted six more months of marketing exclusivity.

continued on page 60

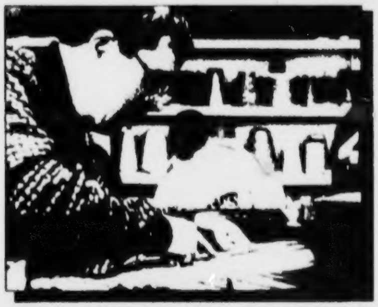
The Meadows at Melmark where...

Life begins at 21!

The Meadows Village Community was established in 1975 at The Melmark Home, a beautiful 80-acre campus located on Philadelphia's exclusive Main Line. At the Meadows adults live with their friends in their own supervised homes, perform meaningful work and have a full life of social, recreational and athletic activities. Self-esteem and enthusiasm for life grow as they experience success every day.

The Sound of Music

Celebrating life's achievements



The satisfaction of meaningful work

Challenging leisure activities

MAKOS
MELMARK
MAKOS

The MEADOWS at MELMARK

A Life Community for Adults with Disabilities

2600 Wayland Road, Berwyn, Pennsylvania 19312
For more information call: Peter McGuinness, Director of Admissions
1.888.MELMARK • www.melmark.org

Circle #57 or visit www.eparent.com/adinfo

THE CENTER FOR CHILDREN • HOSPITAL FOR JOINT DISEASES

Caring for children with
Cerebral Palsy
requires the help of many specialists.

Now you can find them all at
one special place.

The Center for Children is the one place you'll find all the care options you need, with just one concern in mind: your child. By bringing together the resources of the Hospital for Joint Diseases (HJD) and the Rusk Institute of Rehabilitation Medicine (RIRM) of NYU Hospitals Center, we can care for a variety of conditions in one convenient setting. For example, you'll find the widest possible range of treatments for children with cerebral palsy, with in-house specialties including pediatric physiatry, orthopaedics, speech therapy, neurology, neurosurgery, physical and occupational therapy. All in a gentle, kid-friendly environment where there are no white coats, but plenty of color, interaction, toys, games and stimulation. From newborns to 21-year-olds, The Center for Children treats them better. **Call us at 212-598-2330.**

The Center for Children
Hospital for Joint Diseases
301 East 17th Street • New York, NY 10003 • www.jointdiseases.com

For additional comprehensive pediatric services, contact:
NYU Children's Health
866-CHILD-NYU

MOUNT SINAI NYU
HEALTH

Circle #72 or visit www.eparent.com/adinfo

"off-label" drug use

continued from page 58

Meanwhile, physicians prescribe off label because they want to help their patients.

Doctors are now noticing that people with rheumatoid arthritis who take certain types of anti-inflammatory drugs—NSAIDs (nonsteroidal anti-inflammatory drugs) and COX inhibitors—have less colon cancer than the population as a whole. Thus, both categories are being tested for safe and effective use in colon cancer. A situation such as this could lead not only to new approvals, but also add to our knowledge of how certain diseases take form.

Another benefit to off-label prescribing is that it makes drugs available immediately. The FDA approval process for a new drug application (NDA) can take years to complete; approval for an additional indication, while faster, can also take many months or even years. This is a long time to wait for someone who has a severe condition that can be treated with off-label medication.

Sometimes drug companies choose to forgo the formality of FDA approval for additional uses when their products are widely recognized in the medical community as an effective method of treatment—this is often due to the enormous amount of time and money involved in seeking approval. But there are benefits to be had by manufacturers seeking FDA approval. While drug companies are free to circulate third-party studies or articles supporting the off-label use of their products, the FDA stipulates that drugs may not be marketed or advertised for off-label uses. If the potential market and consequent economic benefits are large enough, a company might decide that it is worth the resources to apply for additional approval. Moreover, an approved new indication generally lengthens the period during which the pharmaceutical company has exclusive marketing rights for the product..

This was the case with finasteride, a drug that prevents the production of a male hormone called dihydrotestos-

While drug companies are free to circulate third-party studies or articles supporting the off-label use of their products, the FDA stipulates that drugs may not be marketed or advertised for off-label uses.

1164

Risperidone is quite often prescribed off-label to children to help control behavioral problems associated with conditions such as autism, ADD/ADHD and the depression associated with bipolar disorder.

terone (DHT). Finasteride was originally approved to treat the symptoms of prostate enlargement, but the drug was also discovered to limit male-pattern baldness. With the enormous market for hair-loss prevention therapies, the manufacturer decided to seek approval for the second purpose. Finasteride is now marketed as both Proscar and Propecia, one for each indication.

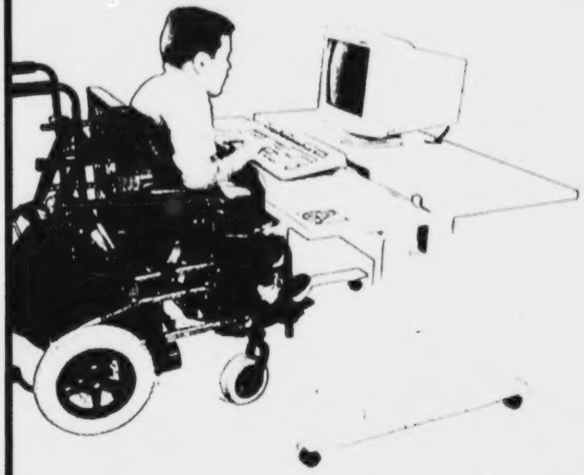
Treatment of neurological and psychiatric disorders often involves off-label uses. Many drugs approved for one condition affect the brain's behavior in ways that are useful for treating other conditions, and so are used for many purposes. Drugs such as fluoxetine (Prozac), a selective serotonin uptake inhibitor (SSRI) approved for treating depression, have also been approved to treat obsessive-compulsive disorder, panic disorder and chronic pain. These drugs are also used off-label to manage severe anxiety, ADD/ADHD and other neurological/psychiatric disorders.

One commonly prescribed psychotropic drug is risperidone (Risperdal). In addition to an approved use for treating schizophrenia in adults, it is widely used for treating schizophrenia in children and teenagers. Risperidone is quite often prescribed off-label to children to help control behavioral problems associated with conditions such as autism, ADD/ADHD and the depression associated with bipolar disorder. The FDA has not approved any drugs for the treatment of autism, but a large number of children with the disorder are helped by taking medication to control problems like aggression, hyperactivity and compulsive behavior. Risperidone is rapidly gaining attention for use in this area and is currently being studied in children with autism.

While off-label drug use can have many benefits, some drugs can also have unexpected side effects. The trick is to make them beneficial; a negative side effect in one situation may become a medical problem-solver in a different context. EP

Reading, Writing and Accessibility

Easy to turn hand crank modifies the task height for each user



Finally, well-designed furniture that easily adjusts in height to fit a child throughout their growth span, while giving facilities the flexibility they require to accommodate multiple students.

AD•AS

To receive a catalog of accessible products from AD•AS call 800.208.2020 or visit us at www.ad-as.com

Circle #18 or visit www.eparent.com/adinfo

CFRI
Conference

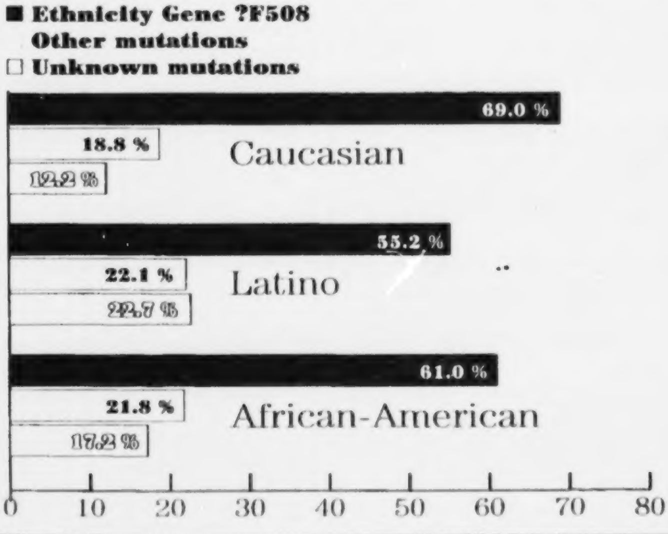
CFRI Cystic Fibrosis Research Inc.
help us save lives

By Jennifer Block Martin

When I went to the Cystic Fibrosis Research Inc. (CFRI) conference in San Jose, California, on August 10, 2002, I brought along my husband, Dave, who himself has cystic fibrosis. The women at the registration table all marveled at how healthy he looked and sounded and at his advanced age, 36. They gave him a name tag that proudly read "CF Adult."

Then one woman asked if Dave was cleared to attend. Each person with CF attending the conference is required to submit a medical release indicating that s/he has never tested positive for Burkholderia cepacia, has not tested positive for methicillin-resistant Staphylococcus aureus within the past two years and is currently not culturing any bacteria resistant to all antibiotics. Although we were sure Dave was clear of these bugs, we did not have proof. So Dave spent the afternoon at the hotel pool while I attended the seminars.

Table 1



If you've ever been to a CF conference or event, you'll understand why such measures are necessary. There is a likelihood of cross-contamination between people with CF. Cystic fibrosis is characterized by the production of unusually thick, sticky mucus that typically blocks the lungs' airways. This consistent mucus production prevents clearance of bacteria, allowing them to colonize and multiply. As a result, chronic infection and inflammation occur, causing persistent coughing, sputum expectoration and wheezing.

Each conference attendee is given hand sanitizer, tissues and a plastic baggie in which to dispose of used items. People with CF are asked to refrain from touching others' utensils and serving items, and even hugging and shaking hands.

With all this in mind, I washed my hands one more time before I entered the conference room.

SCREENING FOR CF IN NEWBORNS

The California Department of Health Services' Genetic Disease Branch (GDB) is charged with developing a fair and efficient newborn screening program. California faces special challenges because of unidentified CF mutations among non-Caucasians, who make up more than 50 percent of the state's births. The GDB's Martin Kharrazi, PhD, who has a child with CF, spoke on this topic.

In 1982, 35 percent of live births in California were of Latino ethnicity, Kharrazi stated. By 2000, that number had risen to 53 percent. With the rise in Latino births has come an increase in CF cases.

In 1999, there were 59 new cases of CF in Caucasians (1/3,000), while there were 28 in Latinos (1/9,000). "We have more than just the white population to deal with," says Kharrazi.

A recent study by the GDB included 900 individuals with CF who were born after 1982 and are linked to California birth records. Table 1, opposite, shows the breakdown of mutation types by ethnicity. Some identified mutations only affected Caucasians, while others were solely found in Latinos or African-Americans. This, Kharrazi says, expresses just some of the intricacies of newborn screening.

BARRIERS TO ACCESS FOR CARE

Deborah J. Kaley, RN, MSN, nursing care manager of the Pediatric Pulmonology department of Children's Hospital of Los Angeles (CHLA) spoke extensively on issues that Latinos in the Los Angeles area encounter, including unreliable transportation, dependence on state aid, smoke and air pollution.

Apparently, this CF center is doing a fine job of reaching its Latino patients. A recent CHLA study of Latinos and Caucasians found that both groups correctly identified the disease process and treatments, and there was no difference in understanding therapy goals. However, Latinos performed more airway clearance treatments. There was no difference in enzyme or vitamin use, nor in the number of clinic visits or hospital days.

While the CHLA has many Spanish-speaking staff members, they feel that Latino families—and Pakistani and Filipino families—would benefit even more from being able to read publications in their own languages.

Kaley noted that the Latino diet may not necessarily be a poorer choice, since people with CF are encouraged to consume more calories than those who do not have CF. She also mentioned that Latinos with CF may appear to be on the lower end of the height and weight scale, but that may also be due to genetics. Kaley also suggested that in the past, Latinos and other ethnic groups may have been passed over for a CF diagnosis because CF was thought of as strictly a "white" disease.

CF AS A CHRONIC, NOT FATAL, DISEASE

Jane Braverman, PhD, states that the outlook for CF has improved dramatically. In 1980, the median life expectancy for patients with CF was 18 years. In 1990, that number jumped to 29. In 2000, it was 32.5. "Cystic fibrosis is now a well-understood, highly treatable and possibly curable disease," she said.

CF can be an isolating disease, especially for those who are not well enough to attend conferences such as this one. Michelle Compton created The Breathing Room, a place for people with CF to have candid, open communications.

Michelle was born in 1967 and diagnosed with CF at age 13. By her 20s, she experienced end-stage CF, including the use of 24-hour oxygen, a wheelchair and a bi-pap ventilator. In December 1998, Michelle underwent a successful double-lung transplant, and has enjoyed excellent health since. In addition to recently earning a bachelor's degree in history, Michelle art-directed Through the Looking Glass: Images of Adults with Cystic Fibrosis, which was on display at the CFRI conference.

Braverman noted that in Denmark, a country known for its rigorous antibiotic CF therapy, people with CF born after 1989 have an 80.4 percent chance of reaching age 45. The probability of surviving 40 years after a diagnosis of CF is 83.3 percent. Minnesota CF Center studies have shown that half of its patients are alive at age 46, and 95 percent of newly diagnosed patients can expect to reach age 21. Another impressive statistic: based on current models, 69 percent of women and 41 percent of men who survive until age 40 are expected to reach age 75.

Braverman reported the title of a recent paper: "Caring for the Geriatric CF Patient." She received a surprised laugh from the audience, which was comprised of hopeful parents, adults and children with CF, caregivers, researchers and health professionals. "Cystic fibrosis has evolved from a fatal disease to a chronic disease," she concluded. EP

For more information visit http://www.thebreathingroom.org. For information on Cystic Fibrosis Research, Inc., see their website at http://www.cfri.org.

Jennifer Block Martin is a writer in San Francisco.

Adapted Bikes Deliver New Independence

Learning to ride a bike is a rite of passage for many children. Its benefits include not only a sense of independence for children, but also better health from regular aerobic exercise, peer inclusion, the ability to participate in family activities, improved self-esteem and improved ability to make decisions. Parents of children with disabilities are often faced with a much larger challenge when trying to teach their children how to ride a bike.

Some parents try training wheels fitted onto conventional two-wheelers to accomplish this task. However, Richard E. Klein, PhD, Lauren J. Lieberman, PhD, Patrick DiRocco, PhD and Elaine McHugh, PhD have developed a new option. They believe that training wheels not only epitomize resignation to the "I can't" mentality, but that there are also shortcomings of training wheels in regards to effective learning of two-wheeled steering and balancing skills.

Instead, they recommend the use of a series of special rollers, an ergonomically correct frame design and gearing modifications. These new rollers contain adaptations necessary for children with special needs to succeed in learning to ride a two-wheeler. By switching to rollers of different crown characteristics in a progressive manner, the aspects of the bicycle/trainer can gradually resemble a typical two-wheeler.

In essence, these new bicycle/trainers act like slow motion machines that tailor the speed and motion, bringing them to a level that the child can manage. With slower forward speed and tipping action, the child is able to focus on task improvement, not bracing against falls. This allows the child to identify and internalize the appropriate responses or actions needed for steering and balancing a two-wheeler.

These researchers found that through use of this technique, some children with special needs have mastered a two-wheeler in as little as two hours, while others take longer. For example, of the approximately ten children with Down syndrome enrolled in their 2001 summer camps, all but one of the children became independent bicycle riders. Other advancement was noticed in children with autism, emotional and behavior disorders, Asperger's syndrome, mild vision impairment and developmental delays. The study also found that this new approach appears to be effective for many individuals with a variety of disabilities, as well as those without.

Top: Thirteen-year-old Kyle Leroux rides a purple bike that has Go-Cart tires.

Left: Seven-year-old Nicole Dahl rides the Bazooka bike with double rollers.

Clockwise from top left: Thirteen-year-old Chloë Dator, thirteen-year-old Kyle Leroux, nine-year-old Tommy Snook and eight-year-old Miranda Caristi .

Criteria for success

Successes were largely achieved in an environment that had an array of adapted bicycles, trained staff and a gymnasium or similar space where the bikes could be used on a clear, unobstructed floor. Peer interaction was also key to the process, as socialization and light competition encouraged the desire to learn. However, there are other factors that were necessary for successful learning:

- The child must have all limbs, be ambulatory and able to grip handlebars.
- The child must be able to pedal and propel a bicycle to a minimal extent.
- The child must have enough control of her/his movements to steer a bicycle.
- The child must have the strength and stamina needed to maintain continued pedaling and exertion that accompanies casual bicycle riding.
- The child must have the vision and/or spatial awareness needed to follow a designed course and avoid objects in their way.
- The child must willingly participate in training and respond to directions.
- The child must want to learn how to ride a two-wheeled bike.

Reasons for Lack of Success

According to the researchers, because of their methods no child has ever failed to achieve mastery of riding due to their inability to balance a bicycle. However, there are factors that could prevent a child from learning how to ride. They include:

- The child does not have the stamina to maintain pedaling because of a disability or chronic condition.
- The child cannot keep his/her feet on the pedals and therefore can't get going. This occurs when the child lacks motor control.
- The child lacks the ability to concentrate on the task of riding.
- The child's behavior precludes participation. For example, the child may display oppositional behavior and/or refuse to follow instructions, participate or wear a helmet.

Making these adapted bicycle/trainers and their associated programs commercially available is still being considered at this time. While a number of prototype bicycle/trainers have been constructed, this is not the same as production. The problem with mass production lies in the fact that the bicycle/trainers must be designed and built to withstand rigorous use. Efforts are underway to engineer the design of the adapted trainers for production, along

continued on page 66

Getting Involved

Practitioners and parents in the disability community commonly ask, "How can I get my children involved?" The following are some suggestions that might help answer this question:

Any neighborhood group, community, agency or institution wishing to sponsor or host a camp or worksheet is encouraged to do so. A local camp must start with you.

Parents or professionals who would like to know more are encouraged to attend existing camps or host a workshop where the methodology can be explained in detail in their area.

Institutions offering camps typically offer open enrollment to any children who are referred.

Inquiries concerning hardware specifics and hardware availability should be directed to Dr. Richard Klein. Email: r-klein@uiuc.edu.

The BEST strollers in the WORLD!
by Baby Jogger

Our Special Needs strollers are lightweight, easy to fold, and a joy to push...

www.babyjog

Circle #70 or visit www.eparent.com/adinfo

HMS Enables Active Learning

HMS School for Children with Cerebral Palsy serves children, ages 2-21, who have multiple disabilities resulting from cerebral palsy or traumatic brain injury. Skilled, compassionate staff and consultants provide individualized interdisciplinary programs that enable each child to flourish and learn.

Day & Residential Programs • Special Education
Physical & Occupational Therapies • Speech/Language Therapy
Music Therapy • Nursing & Nutrition Services • Medical Support
Therapeutic Recreation

State-of-the-Art
Assistive Technology:
Augmentative/Alternative Communication
Computer Access
Environmental Control
Powered Mobility

For more information contact:
Diane L. Gallagher, Ph.D., Director
HMS School
For Children With Cerebral Palsy
– FOUNDED IN 1882 –
4400 Baltimore Ave., Philadelphia, PA 19104
215-222-2566 • Fax: 215-222-1889
www.hmsschool.org
E-Mail: admin@hmsschool.org

Member: NAPSEC • Pennsylvania's Alliance of Approved Private Schools

Circle #44 or visit www.eparent.com/adinfo

continued from page 65

with appropriate tooling to facilitate the manufacture and marketing. EP

The information contained in this piece is based on the report "The Case of the Missing Bicyclist" authored by Richard Klein, PhD, Lauren J. Leiberman, PhD, Patrick DiRocco, PhD and Elaine McHugh, PhD.

Richard Klein, PhD is Director Emeritus of the Bicycle Research Institute for the Department of Mechanical and Industrial Engineering at the University of Illinois in Urbana-Champaign.

Lauren J. Lieberman, PhD is an Associate Professor in the Department of Physical Education at State University of New York (SUNY) at Brockport.

Patrick DiRocco, PhD is an Associate Professor of the Department of Exercise and Sport Science at the University of Wisconsin at LaCrosse.

Elaine McHugh, PhD is an Associate Professor in the Department of Kinesiology at Sonoma (California) State University.

An Instructor's Anecdote

Barbara Robinson, a graduate student in adapted physical activity at the State University of New York (SUNY) at Brockport, is in charge of the Brockport bicycling camp activities, under the direction of Dr. Lieberman. This is her story:

The children involved in the bicycle program at SUNY Brockport have exhibited great progression through the use of the "Adapted Trainer." The children gain confidence each time they ride on the bicycles, in large part because of the almost immediate experience of success. The children determine the level of the bike to be ridden. They inform their instructor whether the bike is challenging enough and when to attempt the next progression.

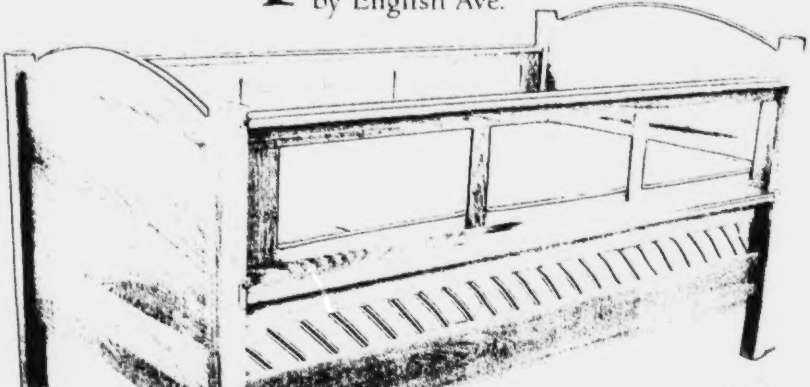
The stability factor of these bicycles is a safety net for the children, but the design also provides a realistic experience as far as tipping over is concerned. The gradual progression from two rollers to one on the back and a conventional tire on the front is a great idea. The design of the adapted trainers puts in place a base of support for the rider, encouraging the feeling of security and confidence while simultaneously providing a realistic challenge for the cyclist to maintain a stable position. It has been observed that if children experience setbacks, they will return to the previous (more stable) trainer, regain their confidence, then advance quite readily back up to the more challenging situation.

The success of our program can be seen by the laughter and smiles on the faces and the exuberance of the students riding freely through the gymnasium.

1170

Once in awhile, something comes along that makes a lot of sense.

The
SleepSafe
Patented
by English Ave.



Ideal for sleeping safely at home!

Adaptive Side Safety Rails
SleepSafe's design is unique to the industry! Put rails up when you need to protect the patient. The clear window reduces claustrophobia. Take them down, or off, as you please.

Reduces Entrapment
Eliminates the gap between the headboard and mattress, as well as the gap between the side rails and mattress.

Built to Last
Rock solid construction keeps sleeping safe and eliminates the gap between headboard/footboard and mattress. SleepSafe's positive locking safety rails insures the patient's well-being. All hardware is adjustable in the field for easy maintenance.

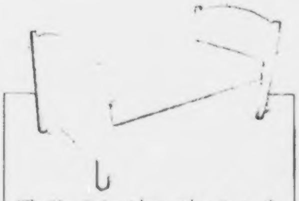
Hello!
Just wanted to touch base and say how much we love your SleepSafer™ bed! Samantha has been resting much better since she's been sleeping in her new bed. I have too!

Angie Leib, Waldorf, MD

New SleepSafe™ Adaptive Safety Bed Meets or Exceeds Safety Standards with Classic Style!

Designed with the advice from caretaking professionals, the SleepSafe™ is manufactured of solid red oak or clear maple and accommodates standard twin size box springs and mattresses.

- Adaptive full-length side safety rails combine the strength of solid wood with clear, acrylic panels and exceed bed safety standards.
- Designed to virtually eliminate the gaps between the headboard and the mattress, as well as the gap between the side rails and mattress.
- The headboard and footboard extend below the mattress, reducing the chance of entrapment.

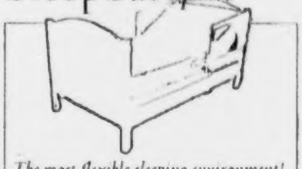


The SleepSafe without side safety rails

SleepSafer

The most secure sleeping environment!

SleepSafe*plus*



The most flexible sleeping environment!

Call Us or Visit us Online!
For more information about SleepSafe Beds, call us toll-free at 866-852-2337, or visit us on the web at www.sleepsafebed.com

www.sleepsafebed.com

The Magic of Snow

by Dorothy A. Levinson

When we were children we were told that there was magic in the very first snowfall of the year and that if we were to build a snowman with this first snow, he would come to life. This past March, I saw a different kind of magic in the snow.

My husband, Jerry, was diagnosed with multiple sclerosis in September 1969, and over the last 33 years I have watched the disease progress. At first, Jerry walked clumsily. Then, after ten years, he began using a cane; after twenty years he needed a wheelchair. Throughout this time, I've continually tried to find ways to make his life easier and as normal as possible.

About a year ago, two very good friends of ours, Pat and Pat De Pinto (simply known as "the Pats"), told us about the United States Adaptive Recreation Center (ARC) in Big Bear Lake, California. They explained that Big Bear Mountain Resort has skiing and snowboarding for people with disabilities.

I immediately picked up the phone to get as much information as possible, and to find out if I could get Jerry on the slopes. I managed to make a tentative appointment with the ARC for him to try skiing. I had never been skiing myself, but had always wanted to try; here was the perfect opportunity for us to have a go at it together.

To the Slopes

We drove to Big Bear Lake and stayed in a condominium located about ten minutes from the mountain. The accommodations were not really handicap-accessible, but we managed. After getting up early and dressing in ski clothes to help us stay warm, we made our way to the slopes. As it turned out, all of the instructors were busy with a busload of children with special needs from a local school, so Jerry did not get to ski.

Right after lunch it began to snow very hard and we found ourselves in the middle of a full blizzard with whiteout conditions. You should have seen the faces of those children, many of whom had never seen snow before. Some of them had physical challenges, some had developmental disabilities, while others had no or only partial vision—but they were all undeterred. They were having a blast!

The children with visual impairments were on skis that were linked at the tips by connectors designed to control their speed. They had tethers attached to their waists so that the instructors, who skied behind the children holding the other ends of the tethers, could give instructions and guide them down the slopes. I saw one child—legs amputated below the knees—on a snowboard closely followed by an instructor. Other children were in special ski chairs accompanied by pairs of instructors. All of them were having the time of their lives. It was magic.

Jean-Claude Levinson

This year I was more determined than ever to get Jerry on the slopes. We called early and were able to get an appoint-

Jerry and his ski instructors guide him through his first lesson.

ment in the middle of March. With much excitement we packed our gear in the car and took off to the mountains with the Pats.

Right after lunch we took Jerry to the ARC at the base of the slopes. First we had to fill out some paperwork that asked about the nature of his disability, how it affected him physically, his height and weight, etc. Then we met with his two instructors, who assessed his needs and abilities and started pulling out the necessary equipment for him to use (the cost was included in the lesson fee).

Before we knew it, Jerry was on a lift going up to the top of the "bunny slope"—the part of the mountain with a gently declining topography for beginners, the timid, and the downright cowardly. Jerry definitely fell into that third category when he started. It was amazing to watch how easily the instructors got him on and off the lift. Once on the ground, Jerry's chair skis just glided down the little slope. One instructor stayed behind him holding the tether while the other was in front of him giving him instructions. Jerry learned how to change directions by leaning to the left or right with "outriggers," Canadian-style crutches with maneuverable skis at the ends that the ARC had supplied.

I couldn't believe what I was seeing: Jerry was skiing! And doing a great job, too. After three runs down the bunny slope, the instructors took him to the top of the beginner slope. It wasn't long, though, before he had conquered that and moved on to the intermediate slope—at 8,600 feet. I couldn't watch him there because I am just not up to that level of skiing yet. Jerry's last runs of the day were down one of the most difficult slopes. He even went off two jumps! Not

continued on page 70

FIRSTFlex™
improving reach, grasp and pinch together.
Caring For Life

FIRSTFlex™, for children with spastic hemiplegia, combines patented bracing with electrical stimulation.

Before Treatment
Posture Grasp
After Treatment
Posture Grasp

www.ultraflexsystems.com
Call 1-800-220-6670 for free video and research studies.

Circle #73 or visit www.eparent.com/adinfo

BLADDER CONTROL PRODUCTS

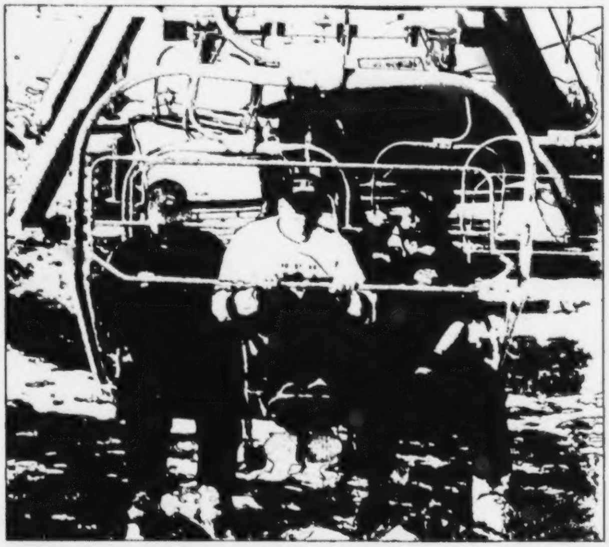
Snuggems
Huggies Supreme
Pull-Ups
GoodNites

Call for your free incontinence products catalog and receive a FREE $25 gift* with your first order.

DMP DURALINE
1-800-654-3376
www.dmponline.com

* Offer expires December 31, 2002. Available only to new customers, with a cash or credit card purchase over $35. Not valid with other offers. $25 gift is not pictured above.
10662

Circle #33 or visit www.eparent.com/adinfo



continued from page 69

of the Winter Olympics type, more like leaping off two ant hills—but "jumps" nonetheless.

I was at the base of the slope when I saw him coming down. He was tearing down the mountain with a huge smile on his face, and his beloved Boston College cap was turned around like a kid's. It was almost as much of a thrill for me to watch Jerry that day as it was for him to be skiing. The whole experience may have gone to his head, though—he's thinking of legally changing his name to Jean-Claude. Clearly, we need to temper his enthusiasm a bit. All the same, we can't wait for the first snow of next fall so we can hit the slopes again.

The ARC

The U.S. Adaptive Recreation Center helps to guide people with disabilities toward the creation and affirmation of rewarding lifestyles. It offers challenging and adventurous recreational programs with excellent instructors and wonderful personnel who are specifically trained to work with the special needs person.

The ARC offers both summer and winter programs. The winter program runs from December to April; the summer program covers July and August, when Big Bear Lake becomes a playground for water skiers, kayakers, sailors, fishermen and jet-skiers. EP

For more information about the ARC go to http://www.usarc.org, or visit http://www.dsusa.org

Dorothy A. Levinson is secretary-treasurer of Benefits Research & Communications, Inc., of San Diego. Her husband Jerry has had MS for more than 33 years.

LAWYERS INCORPORATED, P.C.
AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O. Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Disability Awareness Night at Fenway Park

EP Magazine, in association with the Boston Red Sox, celebrated Disability Awareness Night at Fenway Park on August 20, 2002. The event, which was a huge success, honored Red Sox pitcher Tim Wakefield, Massachusetts State Senator Fred Barry and inventor Bob Hall, as well as the 54 million Americans with disabilities.

The ceremony was held prior to the Red Sox vs. Rangers game. Wakefield was honored for his work on behalf of children with disabilities at the Spacecoast Early Intervention Center in his hometown of Melbourne, FL. Bob Hall, inventor of the wheelchair used by people with disabilities who compete in the Boston Marathon, was also honored.

Also participating in the ceremony were EP Magazine and United Cerebal Palsy (UCP). EP Magazine was founded in Boston 32 years ago, and has been serving the special needs community ever since. It is a source of information and support for many parents, families and health care professionals. UCP is a 52-year-old organization that serves more than a million people with disabilities.

Award winner Bob Hall, the founder of the wheelchair division of the Boston Marathon.

Polaroid
BOBS

Boston Red Sox pitcher Tim Wakefield is honored for his work on behalf of children with disabilities by Ed McCabe, a member of EP's Board of Directors.

DURACELL
Polaroid

Massachusetts State Senator Fred Berry is honored for his work by Esther Schleifer, widow of EP Magazine founder Maxwell J. Schleifer, PhD.

Clay, Danny, Robin and Danielle Wagner live in Fort Lauderdale, Florida. Clay is autistic and has a seizure disorder.

"We're a PediaSure® Family."

"PediaSure helps us give Clay the nutrition he needs."

All kids need proper nutrition for growth and development. If your child is not getting enough of the right nutrition from regular food or has special feeding needs, ask your doctor about the complete, balanced nutrition of PediaSure. It's specially formulated to provide children with proper amounts of protein, fat, carbohydrate, vitamins and minerals. Available in your local supermarket, drug or discount store.

PediaSure
Pediatrician Recommended
Lactose Free

Available through WIC®*

*If your child has special dietary needs, check with your physician or local WIC clinic to see if your child is eligible to receive PediaSure through the WIC program. WIC is a registered trademark of the U.S. Dept. of Agriculture.

© 2001 Abbott Laboratories

Circle #65 or visit www.eparent.com/adinfo

Understanding Dysphagia:
A Parent's Guide

By Debbie Lord, MA, CCC, SLP/L & Lee Barks, RN, MN, ARNP

This is the first of a monthly series written for EP Magazine by members of the American Association on Mental Retardation (AAMR).

Most of us never consider that we might not be able to eat or drink safely; in fact, most people take swallowing for granted. Swallowing, however, is quite complicated. Normal swallowing of food and liquid requires great coordination of a large number of muscles in the mouth, throat, and esophagus (the tube that leads from the throat to the stomach).

It involves many different systems working together quickly, effortlessly, and repeatedly. Normal swallowing is a very quick process, taking less than two seconds to move from mouth through the throat and into the esophagus. We swallow more than 1,000 times in a day. Most of those 1,000 swallows are involuntary, so we never really think about them.

When an individual has a problem swallowing it's called dysphagia. Some of the factors that may have an impact on a swallowing problem are:

☐ Neurologic deficits
☐ GERD (gastroesophageal reflux disease) – backward flow of stomach acid up the esophagus from the stomach
☐ Environment—furniture, overstimulation, feeder, etc.
☐ Previously learned behaviors
☐ Physical disabilities

How we swallow

Swallowing is a combination of purposeful movements and reflexes that normally take no more than several seconds to complete. The entire process can be described in three stages:

☐ Stage one, oral. This is where the food enters the mouth, is chewed and is mixed with saliva. It is then moved backward toward the throat. At the point where the food enters the throat (pharynx) the swallow begins.
☐ Stage two, pharyngeal. This is where the swallow is actually initiated. The food enters the pharynx (throat) at those large arches (facial arches) in the back of your mouth.
☐ Stage three, esophageal. This is where the food enters the esophagus and moves into the stomach.

Types of swallowing problems

There are many different types of swallowing problems. They may exist alone or in combination with each other. It is important to remember that there are many different factors that can contribute to a swallowing problem, and that people often have more than one problem. It is also important to note that each person and problem is different and requires individualized assessment and treatment.

Some of the things that may contribute to a swallowing problem are:

☐ Difficulty closing lips
☐ Difficulty moving/controlling tongue
☐ Weak face muscles
☐ Reduced or absent sensation in mouth
☐ Reduced or absent swallow trigger
☐ Difficulty coordinating various muscles involved in swallowing

Common causes of swallowing problems

Swallowing problems may arise from many different medical conditions or events. Most result in damaged sensations or weakened or uncoordinated muscles involved in swallowing. The following are some things that may cause swallowing problems:

Damage to nervous system

☐ Disorders affecting muscle strength or coordination, such as cerebral palsy or stroke
☐ Progressive neurological disorders, like muscular dystrophy or Alzheimer's disease
☐ Tumors of the head and neck, including malignant tumors
☐ Medication side effects
☐ Medication interactions
☐ Physical positioning problems
☐ Structural abnormalities, such as esophageal atresia or hiatal hernia
☐ Physical environment, for example inappropriate furniture or an overstimulating area
☐ Diet or diet changes
☐ Behavior

Common signs of a swallowing problem

Some people display no outward signs of having a swallowing problem, although most people do give some indication that they are having difficulty swallowing. A list of characteristics to assist in identifying individuals at risk for having a swallowing/feeding problem is given in the box on page 76. Observation of any one or combination of the symptoms/behaviors below may indicate the need for a swallowing evaluation and appropriate medical referrals.

What do you do if you suspect someone has a swallowing problem?

Use the common signs and symptoms checklist. The more information you have, the better.

Talk with or see the child's primary care physician and discuss your suspicions. Provide information that you've gathered from using the checklist. Ask for a dysphagia work-up and a referral to an appropriate physician, if necessary.

Find a speech pathologist (SLP) who performs dysphagia evaluations and who specializes in working with individuals like your child. You may need to consult an occupational therapist (OT) about positioning issues (a seated upright position may not always be the best position for safe swallowing).

Obtain a swallowing evaluation to determine if there is a swallowing problem and if further evaluation is necessary.

Further evaluation may be necessary, which may include an evaluation by an OT, physical therapist (PT), nutritionist and/or behavior specialist, or an evaluation by an ENT (ear-nose-and-throat physician, an otorhinolaryngologist), GI (specialist in gastrointestinal conditions) or pulmonologist (a physician specializing in the lungs and breathing). A video fluoroscopic swallow study may be needed. The most frequently used test for children is a video fluoroscopy (VFSS), which is a modified barium swallow or MBS.

Video fluoroscopic swallow study, or modified barium swallow. A radiologist and a swallowing therapist, usually an SLP, perform this test. A fairly low dose x-ray is administered over a short period, and the study is in motion—an x-ray/video. A small amount of barium, which is opaque ("radiopaque") on the x-ray screen, is mixed with particular textures of food and fluids and presented to the child orally. The swallows are viewed from the front and side. Positioning (usually seated or lying on a side) for the test is important, as are the food/fluid texture and consistency and method of presentation. A familiar person like a parent should present the food/barium and provide support, if possible. It is important to note that anyone will swallow poorly under bad

continued on page 76

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel**. Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #39 or visit www.eparent.com/adinfo

CHECKLIST FOR IDENTIFYING SWALLOWING PROBLEMS:

- Frequent episodes of gagging, coughing or choking
- Coughing or choking during or after eating/drinking
- Difficulty managing saliva (drooling)
- "Gurgling" voice (wet voice) during or after eating/drinking
- Watery eyes during or after eating/drinking
- Frequent upper respiratory infections and/or pneumonia
- Swallowing food whole
- Frequent vomiting
- Regurgitation, hours after meals, particularly while reclining
- Eating rapidly or taking in large amounts at a time
- Extra effort or difficulty chewing or swallowing
- Stores food/drink in mouth
- Loss of food/drink from mouth
- Poor weight gain or unexplained weight loss
- Fatigue or shortness of breath while eating

DANGERS OF A SWALLOWING PROBLEM

If a swallowing problem goes untreated, a person may:

- Become dehydrated
- Lose weight or become malnourished
- Develop aspiration pneumonia
- Be inappropriately medicated
- Become less alert
- Choke
- Potentially die

To prevent any of the above from occurring, children with a suspected swallowing problem should receive careful evaluation followed by appropriate treatment, if necessary.

continued from page 75

conditions. In this diagnostic test, we are trying to determine if the child swallows dysfunctionally under the best conditions, then provide those needed supports on a daily basis.

Upper GI series. This test usually includes a barium swallow and also continues viewing down the esophagus, into the stomach. It is used to rule out abnormalities of the esophagus and upper stomach.

Endoscopy, usually esophago-gastroduodenoscopy (EGD). This is direct visualization of the inside of the esophagus, stomach and duodenum (first part of the small intestine) through a fiberoptic scope, to look for abnormalities like overgrowth of certain cells, pouches (diverticula), ulcers or erosion. Tissue may be biopsied in this procedure, which is most often used in adults.

Esophageal pH monitoring. When stomach acid flows back upward into the esophagus (gastro-esophageal reflux or GER), the pH of the esophagus becomes more acidic. This test may be used to distinguish between aspiration (flow of food or fluid into the upper airway and trachea) that occurs during the swallow (dysphagia), and aspiration that occurs during GER. In the test, a probe (long wire with an acid sensor on the end) is put into the esophagus for a length of time. If the sensor detects an acid pH, the test may be considered positive for reflux. It is not often used in young children because of the difficulty of maintaining the probe in place for a sufficient length of time or of pulling out the probe.

Gastric emptying test, or gastric emptying time (GET). This determines a representative time the stomach takes to empty under usual conditions. It can be important, because delayed stomach emptying may "set up" GER, often resulting in aspiration. This process mimics dysphagia in producing aspiration. When the stomach can be influenced to empty into the duodenum in a reasonable length of time, GER may be prevented.

Salivagram. This test "tags" saliva and "detects" its presence when it flows into the trachea and lungs. Aspiration of saliva can be responsible for lung inflammation (pneumonitis).

Important consideration for follow-up

Once an evaluation is complete and it's determined that a plan of support for dysphagia is needed, it must be developed with both health and lifestyle considerations in mind. It is important to integrate the desired clinical, medical and functional outcomes with the individual's personal outcomes and desires.

It is important to consider the following:

☐ How important to the child is drinking independently?

☐ Does the child have hobbies or

WEBSITES
http://dysphagia.com
http://www.dysphagia-diet.com
http://www.asha.org
http://www.eatright.org/adap027b.html
http://www.alimed.com

SUPPLY RESOURCES:

Sammons Preston
P.O. Box 5071
Bolingbrook, IL 60440
(T) 1-800-323-5547
(Fx) 1-800-547-4333

North Coastal Medical
18305 Sutter Blvd.,
Morganhill, CA 95037
(T) 1-800-821-9319
(Fx) 1-877-213-9300

Alimed, Inc. Order Dept.
297 High St.
Dedham, MA 02026
(T) 1-800-225-2610
(Fx) 1-800-437-2966

things that s/he really enjoys besides eating?

- Does the child eat independently? Does s/he want to remain independent, or as independent as possible?
- What is the most important thing to the child relating to mealtime?
- Is the child very social during mealtime?
- Are the child's likes and hopes being taken seriously?
- Can the child be switched to a less restrictive diet, if other medication changes are made?
- What can we do to best combine the child's wishes with his or her healthcare needs?

As with all health-related information, the definitive source to help you address your child's needs is your primary care provider (physician or nurse practitioner). For more information about dysphagia and qualified professionals in your area, please refer to the American Speech and Hearing Association (ASHA). Other important websites are listed.

Debbie Lord, MA, CCC, SLP/L is the Director of Clinical and Healthcare Services at Ken-Crest Services, Plymouth Meeting, PA. She can be reached at dlord@kencrest.org. Debbie is a Fellow and active member of AAMR.

Lee Barks, RN, MN, ARNP is the President of Developmental Health Care Inc., Longwood, Florida. She can be reached at develophealth@msn.com. Lee is a Fellow and active member of AAMR.

REFERENCES

Arvedson, J.C. & Brodsky, L (Eds). (1992) Pediatric Swallowing and Feeding, Assessment and Management. San Diego: Singular Publishing Group.

Carrau, R.L. & Murry, T.M. (1998) Comprehensive Management of Swallowing Disorders. San Diego: Singular Publishing Group.

Croft, R.D. (1992). What Consistency of Food is Best for Children with Cerebral Palsy: An Ultrasound Investigation. Dysphagia, 10, 155-159

Groher, M.E. (1992). Dysphagia Diagnosis and Management, Second Edition. Butterworth-Heinemann, of Reed Publishing

Rosenthal, S.A., Sheppard, J.J. & Lotze, M. (1995) Dysphagia and the Child with Developmental Disabilities. San Diego: Singular Publishing Group.

Wolf, L.S. & Glass, R.P. (1992). Feeding and Swallowing Disorders in Infancy, Assessment and Management. Tucson, AZ: Therapy Skill Builders.

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

Toys to Enhance Development in Brain Injured Children
by Richard A. Neubauer, M.D., Medical Director

Hyperbaric oxygen is capable of arousing dormant, idling brain cells that have suffered some form of damage, which is characteristic of all CP and brain injured children. The extent of this damage may be seen by functional brain imaging, and the results of any type of therapy, especially hyperbaric oxygenation, may be gauged by improvement in blood flow and metabolism as shown on repeat scans.

As new cells develop in little ones, or as dormant idling cells begin to fire electrically in older children, they need a sense of direction. To provide this, we recommend PT, OT, speech therapy, and at times acupuncture and appropriate counseling.

However, the role of educational, age-appropriate toys must not be overlooked. Toys should be chosen that will encourage developmental progress in the child. Building blocks, shape sorters and color matching games are among the various playthings that promote important fine motor and sensory skills. As children get older, certainly computers play a major role. Stereo players with motivational music tapes such as those from the Monroe Institute in Virginia* will also enhance development. Thus, when the parents of children with special needs look for toys, they should look for educational playthings that can be motivational aids in learning; entertaining items that will also play a beneficial role in their child's development.

** For additional information, visit the Monroe Institute's web site at www.monroeinstitute.org.*

Announcing...
The 3rd International
Symposium on
Hyperbaric Oxygen in
Cerebral Palsy and the
Brain Injured Child
Richard A. Neubauer, M.D.,
Symposium Director
July 16-19, 2003
Fort Lauderdale, Florida
For information:
(800) 552-0255
symposium@oceanhbo.com
www.oceanhbo.com

(800) 552-0255
• Call for free video & information

For more information, visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

Circle #60 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of hyperbaric oxygen therapy. For Editor-in-Chief statement see our Contents page.

Gynecological and Reproductive Healthcare for Women with Special Needs

By Catharine A. Kopac, PhD, GNP

This is the third article I have authored for EP in 2002 on gynecological and reproductive care for teenage and adult women with special needs. In February and May I reported the findings of two research studies conducted over the past decade. This article will outline issues that parents, direct support professionals (DSPs), health care professionals and teenage and young-adult women themselves face as they access gynecological and reproductive health care. It also describes approaches that parents, DSPs and primary care providers who support teens and young women with developmental disabilities have found to be helpful.

A Matter of Attitude and Perception

Heightened advocacy for people with special needs has resulted in a greater awareness of their need for comprehensive, quality health care. Unfortunately, not all areas of health care have received equal attention, and gynecological and reproductive care still remains outside the awareness of most primary care providers. One reason for this is that many providers do not believe they have adequate training to serve young women with special needs, and thus feel ill-equipped to deal with emotional and behavioral issues that may arise.

Another reason that teens with special needs do not receive care is that their parents and DSPs do not believe that these young women are sexually active and that, therefore, gynecological check-ups are unnecessary. While this point of view is common, it is often inaccurate. Many teens and young women are indeed sexually active and may not wish to disclose this to their parents. Even when not sexually active they still need to be tested for cervical, ovarian, and uterine cancer, especially as they get older. While sonograms can test for some types of cancer, a PAP smear is essential for the detection of cervical cancer. If women learn about their bodies from an early age, and meet regularly with a primary care provider who provides gynecological care, they will be much more likely to participate in and accept the regular care that is recommended.

An important consideration is the high rate of sexual abuse of young women with developmental disabilities. Primary care providers are in a strategic position to screen for and identify abuse of these vulnerable young women. If teens are seen early for gynecological care, particularly by a provider who is sensitive to abuse issues, they will be better equipped to avoid sexual abuse and to report it.

Anticipating Special Needs & Finding a Provider

For parents, DSPs, primary care providers and the young women themselves, the major barrier to gynecological care is often the young person's fear of the office visit or the exam. This fear, when perceived by the parents, DSPs and providers, is often a key factor contributing to the reluctance with which everyone approaches the needed gynecological care. Parents and DSPs don't want to cause unnecessary anxiety—which can often lead to acting-out behaviors—and some providers will try to avoid difficult persons. There are a number of things that can be done by both the parents/DSPs and the primary care providers to decrease fear and facilitate the office visit.

Research Tips For Caregivers

- Network with other parents/DSPs—find a provider who is known to offer care to young women with special needs, even if the provider is geographically outside your local community.
- Visit the office where the visit is to take place and determine if your teen's special needs can be met. If she has limited mobility and requires a lift onto an exam table, is there someone in the office who can provide assistance? Is the office wheelchair-accessible? Determine who will actually perform the exam. Meet that person and tell him/her about your teen's special needs. If sedation has been used for procedures in the past, it is helpful to let the provider know.
- If you do not believe that your teen is capable of informed assent (passive acceptance of a clinical action or participation), the provider should know this and understand how you have arranged health care in light of this issue.
- If your daughter is 18 years of age or older, informed consent is desirable for medical decision making. Remember that adults are usually afforded the opportunity

to give informed consent for clinical interventions. Unless the young woman is well prepared in advance she may not consent to an exam that she fears.

Routine pelvic examinations, PAP smears and mammography do not require written informed consent. However, primary care providers will rarely perform examinations or procedures on people who do not have some level of understanding about what is being done.

- Whenever possible, the provider should know if the young woman is sexually active. A provider who knows about sexual partners and can incorporate a discussion about them into the visit is better able to individualize examinations and health education of the young woman.
- Young married women with special needs should make every effort to have their husbands accompany them on the visit. The presence of a spouse may be reassuring during a pre-examination discussion and, for some women, during the exams themselves. Both husband and wife can benefit from the health education opportunity.
- Determine whether the provider will reserve the additional time that may be required for the exam.
- If you have a teen with behavior problems, scheduling the appointment so that it is the last in the day may be a way to avoid difficult situations in waiting areas.
- If a visit to the home of the teen would be best to perform examinations, inquire about this possibility.
- Remember to verify that the provider will accept the payment plan that is available to your teen (Medicaid, HMO, PPO). Some providers do not accept Medicaid persons and/or a provider may not be part of her plan coverage.

Hints For Primary Care Providers

Office staff require education about caring for persons with special needs.The following are some ideas that can aid in educating staff members about what is required of them during an appointment with a person with special needs.

- It may be necessary to have special continuing-education offerings for both professionals and support staff to discuss specific disabilities and their management.

continued on page 80

Anderson School

Building A Tradition of Service for Over 78 Years

Anderson School provides the highest quality programs possible for children (ages 5-21) and adults with autism and other developmental disabilities. Anderson School is an educational residential community committed to an ongoing and fully integrated support network for their families and guardians. As an organization, Anderson School constantly strives to provide an enriched and positive climate filled with educational, cultural and recreational activities designed to foster continuous growth, independence and social interaction.

Located near historic Hyde Park (approximately 95 miles from midtown Manhattan) on a scenic 100 acre wooded estate overlooking the Hudson River, Anderson School serves all of New York State and welcomes out of state applications.

Now Accepting Referrals

- Residential and day students welcome
- Students accepted throughout the year

Call Kate Haas, Director of Admissions (845) 889-4034 Ext. 534
4885 Route 9, Box 367, Staatsburg, New York 12580-0367
www.andersonschool.org E-mail: katehaas@andersonschool.org

Circle #19 or visit www.eparent.com/adinfo

1183

continued from page 79

- Special procedures may need to be developed for planning and executing visits of teens and young women with special needs.
- Carefully selected educational materials should be available for the parent/DSP and the young woman. It would be wise to provide some of this material well in advance of the visit.
- The office environment should be assessed to determine if it can accommodate young women with special needs.
- The office should be physically accessible to wheelchairs, walkers and other mobility devices.
- Wait times should be limited; scheduling should be done at the beginning or the end of the day to limit wait times
- The space used for the exam should be selected with care. Some teens and young adults make noises that can be alarming to other people. Thus, it would be better to use an examination room at the end of the hall or somewhat separated from others.

> **A health care professional can perform no greater empowering act than to teach someone to care for herself, and so it is with the teenager with special needs.**

- The office may need to be customized to allow for exams on the floor (an exercise mat can be covered with disposable paper) or a sofa, as some people with disabilities simply cannot use stirrups.

The Gynecological Office Visit

The first office visit for a gynecological examination can be a stressful experience for all concerned. However, there are certain approaches that will facilitate the provision of care. A good gynecological visit for a teenager or young adult woman would include a gynecological history (onset of menses, menstrual problems, frequency of menses, etc.), pelvic examination and PAP smear, clinical breast examination and education tailored to the needs, concerns and abilities of the teen or young woman.

Ideas for Parents/DSPs

- Prepare the teen in advance for the visit. No one likes to be surprised with procedures as intimate as those required in breast and pelvic examinations. Pictures that show what will be done are often helpful. The young woman needs to be reassured that she will not be left alone with a stranger. If your teen says that she would like to see the provider alone, her choice should be respected.
- Schedule the visit for a day when the young woman is not likely to be menstruating.
- Before the appointment, anticipate some of the questions that the provider may ask and help your teen think about them; eg, when did she last menstruate?
- Explain at home the need to get undressed and help your teen to select clothing that is easy to remove or accessible for the provider.
- If appropriate, say that you would be willing to have the provider examine your breasts first so that she can watch. This should be arranged with the provider in advance. Some providers will demonstrate aspects of the exams on themselves.

Recommendations for Primary Care Providers

- The person must be greeted as a person and spoken to directly even if the parent or DSP responds to questions. Try to elicit some responses from the young person herself.
- Spend time getting to know the teen and determine what she can understand.
- It may be necessary to discuss the examination on the first visit and schedule a second visit to the exam.
- Determine if the teen wants a family member/DSP in the room with her while the exams are being done.
- Flexibility is key. If the person cannot or will not get on a table, a predetermined alternative should be available.
- Alternative positions may need to be used when doing the pelvic examination (Planned Parenthood offers "Table Manners," a helpful guide).
- As the exam is being done, continue to talk to the teen and reassure her.
- The provider should be prepared to show where s/he is going to touch the young woman.
- If all else fails and the young woman refuses the exam or refuses to cooperate, a sedative or even general anesthesia may be necessary.
- Pregnancy status must be checked.
- Testing for STDs is important and should be done every six months, depending upon sexual activity. Chlamydia is a big problem within this population, and its presence will confirm that the young woman is sexually active.
- Sonograms can help to determine certain diagnoses and may eliminate the need for more invasive procedures.
- It is not uncommon for persons with special needs to be incontinent during a pelvic examination; the provider should reassure the young woman (particularly if this is her first exam) and her parent/DSP that this sometimes happens and isn't an issue.

- Screen for abuse. Signs of abuse include bruising, struggling or "fighting" the exam and a stretched vagina.

Consumer Education

A health care professional can perform no greater empowering act than to teach someone to care for herself, and so it is with the teenager with special needs. All too often, though, in an attempt to hurry through a clinical encounter, teaching is overlooked and information is given to the parent or DSP who appears to understand more readily.

Whenever possible, the young woman should be taught how to care for herself, thus reinforcing the responsibility of tending one's body in an appropriate way. Education about health is a cooperative endeavor

continued on page 82

Consumer Education Materials

There are many sources of education literature available for both the parent/DSP and the primary care provider. It is imperative that materials be selected carefully and matched to the individual. Many of these items are available from organizations that can be accessed on the World Wide Web. The abbreviated list below is a place to start:

Disabled Women's Sexual and Reproductive Health Resource Packet
 http://www.prodworks.com/ilf/sr_info.htm
The Epilepsy Foundation
 http://www.efa.org
Health Promotion for Women with Disabilities Project, Villanova University
 http://www.nursing.villanova.edu/WomenWithDisabilities
Muscular Dystrophy Association
 http://www.mdausa.org
Multiple Sclerosis Society
 http://www.nmss.org
Sexuality and Developmental Disabilities Resources
 http://www1.nhchallenge.org:82/
 click on "need help?" pick "sexuality resources" from menu
Sexuality Information and Education Council of the United States (SIECUS)
 http://www.siecus.org/pubs/biblio/bibs0009.html
United Cerebral Palsy Association
 http://www.ucpa.org

NEVER GIVE UP THE SEARCH TO FIND THE RIGHT PLACE...

"I was advised to settle for something less, but kept searching. When I visited Crotched Mountain there was a tangible difference in attitude– a professionalism, respect, and "can-do" attitude that set them apart. Standards are high and the approach genuine–they really care! I am very happy with Crotched Mountain and most importantly, so is my son Jared. He has grown enormously in many ways and is becoming the young man that I always thought he could become. It's a family's dream, come true!" —*Kathy Berns*

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@crotchedmountain.org

CROTCHED MOUNTAIN
OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #29 or visit www.eparent.com/adinfo

1185

continued from page 79

between the parent/DSP and the primary care provider, who can each approach the teenage woman in an individualized way that recognizes her ability to understand and participate.

Special education materials have been developed for this population. Their education should include:

- Hygiene
- Safe sex practices and birth control
- How to maintain a calendar and keep records of the menstrual cycle
- What clinical breast examinations are and how/why they should be performed

I am reminded of a conversation that I had with an adult woman who had cerebral palsy. Although she had loving parents, her gynecological care was virtually ignored. She was in her twenties when she had her first pelvic examination and it was a painful, embarrassing experience. She did not seek care again until, in her thirties, she had a problem that needed treatment. This led to another negative experience and then, finally, a friend who also had cerebral palsy told her of a gynecologist who cared for a large number of women with special needs.

She now flies nearly 2000 miles per year to get her routine pelvic examination and PAP smear. She believes that her efforts to see this special physician are worth it because she receives good care and she trusts the physician. She is fortunate to have both the "great" physician and the resources to visit him each year. One wonders how many teens and women go without care because they cannot find a provider and/or they lack resources.

In the May 2002 EP article I discussed barriers to care experienced by adolescents and women with special needs. The two barriers most frequently cited in a study of 727 practicing nurses were:

1) a lack of empathy and/or knowledge on the part of the healthcare providers, and

2) difficulty finding providers who were willing to care for women with developmental disabilities.

Given these two issues, it is imperative for parents/DSPs and providers alike to seek gynecological and reproductive health care for their teenage daughters earlier rather than later. If the gynecological examination and visit are seen as routine, as she matures the young woman is much more likely to view it as a part of responsible preventive health care. **EP**

The High-Low Chair
The Updown Chair

The LadyBug Corner Chair
The Convert-Able Table

Seating and
Positioning
Products
for Children

R.E.A.L. DESIGN
Rehab and Educational Aids For Living
Phone : 1-800-696-7041
Fax : 1-315-429-3071

Circle #63 or visit www.eparent.com/adinfo

Catharine A. Kopac is currently a primary care fellow in the Center for Clinical Bioethics at the Georgetown University Medical Center in Washington, DC. At present she has a research and practice interest in three vulnerable populations: persons with Alzheimer's disease, older adults requiring long-term care and women with developmental disabilities.

This material was excerpted from Kopac, C and Fritz, J (2002). The Availability and Accessibility of Gynecological Services for Women with Developmental Disabilities: A Nursing Perspective, an article submitted to the Journal of Women's Health and Gender Based Medicine.

The author would like to acknowledge two people who were invaluable in the development of this article. Vera Thomas, a nurse-midwife with many years of experience in serving young women with special needs, for very unselfishly giving of her time in consultation, and Joni Fritz, my research collaborator, who has 30 years of experience in the field of developmental disabilities, for providing expert advice and editorial support.

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at
DISCOUNT PRICES!

As a service to our customers, we offer
FREE SAMPLES
of disposable youth briefs and pull ups.

GoodNites
GoodNites
GoodNites

Save up to 50%
Call **1 800 777 1111** 24Hrs
WOODBURY PRODUCTS, INC.
Order online at: **www.woodburyproducts.com**

Circle #75 or visit www.eparent.com/adinfo

THE
Adjustable
Bath Chair
by DURALIFE

30L-B
30M-B

- 9" leg extensions available.
- Adjusts to multiple positions for individualized comfort.
- Safe, quick push-button adjustment mechanism located out of child's reach.
- Highly-durable, comfortable mesh fabric is easy to clean and dries fast.
- Safety straps included for those who require extra support.

TWO great styles to choose from!

Model 20
Model 350
Pediatric Shower/Commode Chair

DURALIFE, INC.
Call Toll Free: 1-800-443-5433
Fax: 570-323-9762
E-mail: duralfe@aol.com
Website: www.duralife-usa.com

Circle #32 or visit www.eparent.com/adinfo

est. 1978
Consumer Care™
Rehab Specialties Division

Special Purpose Products for Special Persons and Those Who Assist Them

See Our New & Expanded Catalog on Adults & Children

VISIT Our Easy To Use & Fast Access Web Site
www.consumercareinc.com

- See & Learn about Products & 3M Supplies
- Obtain Dealer Referrals
- Positioning Management Programs
- Lease/Rental Options
- Trial Use/Evaluations
- News & Valuable Tips

Consumer Care Products Inc. Rehab Speciality Division
1446 Pilgrim Road, Plymouth, WI 53073, U.S.A.
Tel: 920-893-4614 or FAX: 920-893-6195
E-Mail: ccpi@consumercareinc.com

Circle #28 or visit www.eparent.com/adinfo

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Serving Adults having MR/DD

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

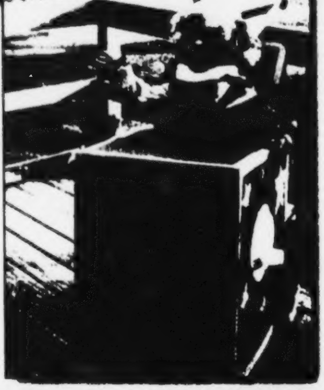
Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #20 or visit www.eparent.com/adinfo

1188

Happy Halloween
SOME CREATIVE & SAFE IDEAS

Jake and Nell dressed as Disability Rights Lawyers in Business attire. Their mother is wearing an old graduation gown to pose as the judge.



Tyler Frey enjoyed posing as a very colorful "Jack in the Box" for Halloween in 2001.

Cardboard, felt, magic markers and a lot of love help make Austin's wheelchair into Dale Earnhardt Jr.'s #8 car. A big thanks to Aunt Deb's creativity.

EP

NEVER PAY FULL PRICE AGAIN!!
EP PREFERRED BUYER CLUB OFFER!

EP
PREFERRED
BUYER
CLUB!!

A Charter Membership in the EP Preferred Buyer Club includes the following special benefits:

- * A personalized EP Membership Card
- * 10% Discount on all books in the EP Library
- * 10% Discount on all videos in the EP Library
- * 20% Discount on all EP Monographs and Special Reports
- * $7.50 Discount on annual subscription to EP Magazine or renewal during term
- * One free ticket to the World Congress Exposition on Disabilities
- * Gift Certificate for FREE SHIPPING on next order
- * Only $24.95 per year

Take advantage of this dynamic offer now!
You can sign up any one of the following ways:
CALL 800-535-1910 or Visit
www.eparent.com & www.eplibrary.com

YES!! I want to join the EP Preferred Buyer Club so that I won't have to pay full price again !

Mail to: Exceptional Parent Dept: Membership P O Box 1807 Englewood Cliffs, NJ 07632-1207
Or Order on-line: www.eplibrary.com/epreferredbuyerclub/ Fax (201-947-9376 Or call 800-535-1910

Name: ______________________________
Address: ______________________________
City: ____________________ **State:** __________ **Zip Code:** __________
Telephone: ____________________ **Email:** ____________________

I have enclosed my check payable to Exceptional Parent or charge to my:

☐ VISA ☐ Mastercard ☐ AMEX ☐ Discover

Account Number: ____-____-____-____ **, Exp. Date:** ___/___ **Signature:**

Circle #200 or visit www.eparent.com/adinfo

IN MEMORIAM

Diane J. Lipton (1945-2002)— Disability Rights Leader

Diane Julia Lipton, the Director, of the Children with Disabilities Advocacy program, at the Disability Rights Education and Defense Fund (DREDF), died at the age of 57. She struggled with cancer for two years. Lipton found her calling when her daughter, who has Cerebral Palsy, was segregated and deprived of her educational rights as a child in the Richmond, California School System. Diane began advocating for her own child and then became a nationally recognized spokesperson for the rights of children with disabilities to receive integrated, appropriate, dignified educational services. With other parents, Diane was able to orchestrate the closing of all disability-segregated schools in Richmond.

She received a number of awards and honors including two American Jurisprudence Awards, and the Distinguished Parent Award, from the Association for Severely Handicapped (TASH). Honors and awards also came from the Developmental Disabilities Council, and the National Center in Educational Restructuring and Inclusion.

The family has requested that contributions be made either to the Disability Rights Education and Defense Fund in Berkeley, California, or to East Bay Innovations in Oakland, California.

Dr. Henry Enns Dies at 59

It is with deep regret that the Board of Directors and the staff of the Canadian Centre on Disability Studies announce the sudden death of Dr. Henry Enns, Executive Director of the Centre, on August 12, 2002. Dr. Enns was a pioneer, an activist and a visionary for people with disabilities. He was a leader at the local, national and international level all his working life.

Dr. Henry Enns most recent work, the Canadian Centre on Disability Studies (CCDS) embodied his vision of an integrated approach to understanding disability. The Executive Committee of CCDS has appointed Dr. Deborah Steinstra as Acting Executive Director and remains committed to Henry's work and the Committees' collective vision. The work of the CCDS continues as an important legacy to the memory of Dr. Henry Enns.

NBC Soap "Passions" Loses Star

Josh Ryan Evans, "Timmy" of NBC's "Passions," passed away on August 5, 2002 at 20, due to complications stemming from a long-time congenital heart condition. Josh was diagnosed at a young age with Achondroplasia, a rare disease and form of congenital dwarfism that prevented his body from maturing and restricted cartilage growth and physical development.

Josh was 3'2" tall and famous for using his size as an asset as his features allowed him to play both child and adult roles believably. He was a star on "Passions" since its debut in 1999, has appeared on "7th Heaven" and "Ally McBeal" starred in "Dr. Seuss' How the Grinch Stole Christmas" (2000) and has also done voice-overs on the Nickelodeon series "Rugrats" and "Hey Arnold."

At his family's request, donations may be sent in Josh's name to the Make-a-Wish Foundation in lieu of flowers. Donations may be made via phone at 1-800-880-1382 or online at www.makeawish.org.

New Aviation Hotline from Department of Transportation

On August 5, 2002, the Department of Transportation's aviation consumer disability toll-free hotline became operational. The toll-free number for the aviation consumer disability hotline is (866) 266-1368 (voice) or (866) 754-4368 (TTY)

New Web Site for Direct Support Professionals

The National Alliance for Direct Support Professionals has posted their new web-site at www.nadsp.org. The group is composed of individuals and organizations, such as ARC, The United Cerebral Palsy Association and The American Association of Mental Retardation. It is intended to help correlate and strengthen the efforts of the direct support workforce. These aids encourage and help children follow their goals and dreams, whether it is rehabilitation, education, or a career.

10 Lucky Kids Win Scholarships

Frosted Flake mascot Tony the Tiger turned 50 years old on August 16, 2002 and Kellogg CEO Carlos M. Gutierrez awarded all ten finalists in the company's contest for "courageous and inspirational" children a $10,000 scholarship. The winners, which included a blind child who teaches Braille and a ten-year-old living with cancer and hemophilia also met Rosie O'Donnell and Nick Carter during the celebration.

continued on page 89

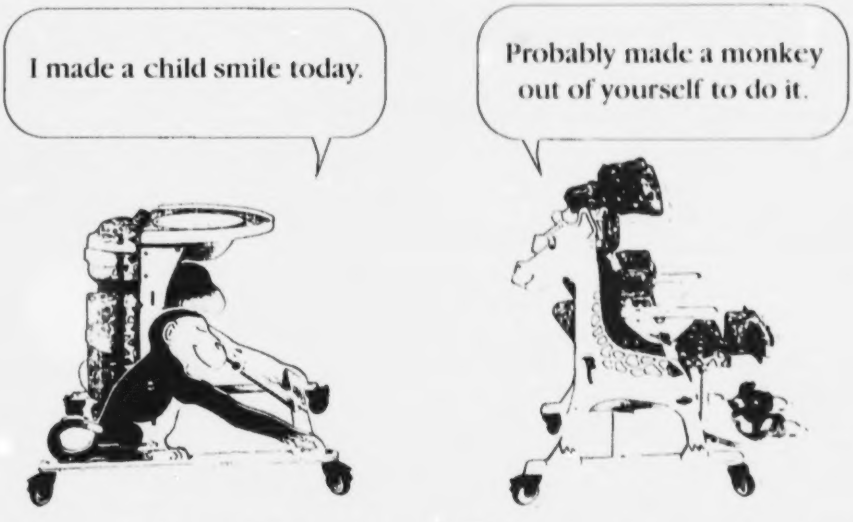
Changing
Lives
Forever

The Anne Carlsen Center for Children offers a 60-year tradition of residential, therapeutic and educational services on one campus. Our individualized services include care for children and young adults coping with cerebral palsy; orthopedic, vision and hearing impairments; autism, pervasive and other developmental disorders; and many other medical challenges. Our multidisciplinary team can reach out to you by conducting evaluations in your child's home and school setting.

**Anne Carlsen
Center for Children**
Changing lives forever

Jamestown, North Dakota
Call 1-800-568-5175 or visit our
web site at: annecenter.org

Circle #21 or visit www.eparent.com/adinfo


I made a child smile today.
Probably made a monkey out of yourself to do it.

Jenx. The most serious children's positioning equipment you can get.

JENX

The perfect positioning. For body. And soul.

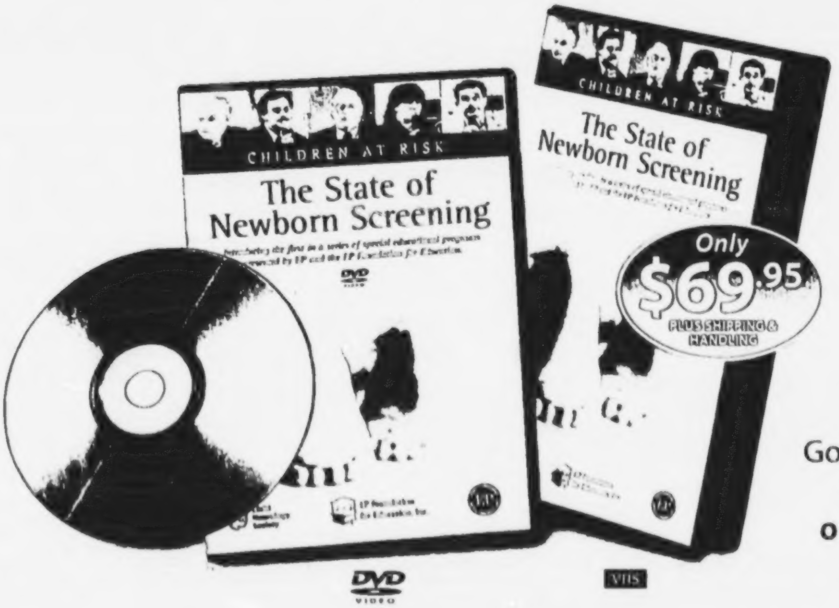
Distributed by BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104

Visit us at the World Congress & Exposition on Disabilities. Booth #0713

Circle #24 or visit www.eparent.com/adinfo

What is Universal Newborn Screening?

This could help change the
quality of your child's life


CHILDREN AT RISK
The State of Newborn Screening
CHILDREN AT RISK
The State of Newborn Screening
Only $69.95
PLUS SHIPPING & HANDLING
DVD VIDEO
VHS

EP Foundation for Education, Inc.

Child Neurology Society

EP

Go to: www.eparent.com
for more information

ORDER THE DVD NOW!

Darryl DeVivo, MD SIDNEY CARTER PROFESSOR OF NEUROLOGY COLUMBIA UNIVERSITY	*Piero Rinaldo, MD, Ph.D.* DIRECTOR, BIOCHEMICAL GENETICS LABORATORY MAYO CLINIC	*Edwin Naylor, Ph.D.* PRESIDENT NEOGEN SCREENING, INC.	*Joan E. Pellegrino, MD* ASST. PROF. OF OB/GYN & REPRODUCTIVE SCIENCES UMDNJ, ROBERT WOOD JOHNSON MEDICAL SCHOOL	*Paul M. Fernhoff, MD* MEDICAL DIRECTOR EMORY UNIVERSITY GENETICS LABORATORY

Your DVD or VHS can be ordered today by calling toll-free

800-535-1910

or online at

www.eplibrary.com

VISA CHECK

To request more information on this program, use the reader service card below or visit us on the internet at www.eparent.com

Circle #45 or visit www.eparent.com/adinfo 1192

CALENDAR

OCTOBER

DISABILITY AWARENESS MONTH

NATIONAL DEPRESSION SCREENING DAY, OCT. 10
National Mental Illness Screening Project (781) 239-0071

NATIONAL OSTEOPATHIC MEDICINE WEEK, OCT. 6-12
American Osteopathic Association (800) 621-1773 x8252

MENTAL ILLNESS AWARENESS WEEK, OCT. 6-12
American Psychiatric Association (888) 357-7924

NATIONAL BRAIN INJURY AWARENESS MONTH
Brain Injury Association of America (703) 236-6000

NATIONAL LUPUS AWARENESS MONTH
Lupus Foundation of America (800) 558-0121

NATIONAL PHYSICAL THERAPY MONTH
American Physical Therapy Association (703) 684-2782 x3248

RETT SYNDROME AWARENESS MONTH
International Rett Syndrome Association (800) 818-RETT

NOVEMBER

GERD AWARENESS WEEK, NOV. 24-30
International Foundation for Functional Gastrointestinal Disorders (888) 964-2001

AMERICAN DIABETES MONTH
American Diabetes Association (800) 232-3472

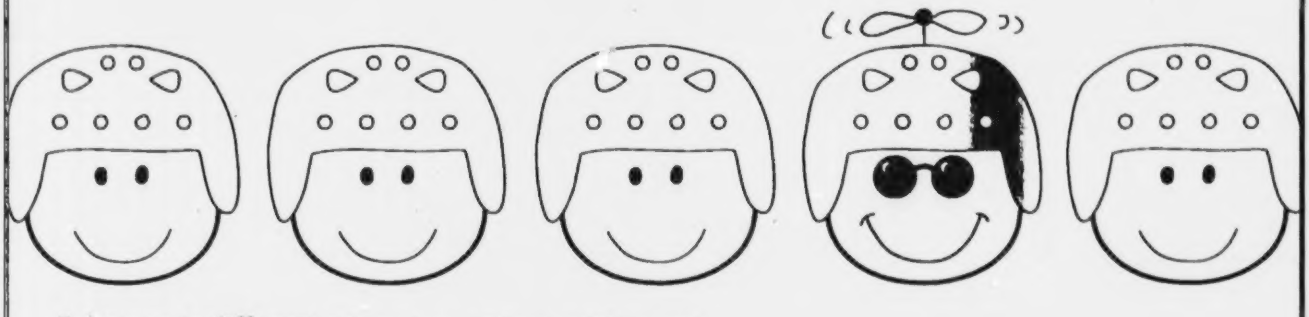
NATIONAL MARROW AWARENESS MONTH
National Marrow Donor Program (800) 627-7692

NATIONAL HOSPICE MONTH
National Hospice and Palliative Care Organization (703) 837-1500

NATIONAL EPILEPSY MONTH
Epilepsy Foundation (800) EFA-1000

NATIONAL ALZHEIMER'S DISEASE AWARENESS MONTH
Alzheimer's Disease and Related Disorders Assoc. (800) 272-3900

Customized Smiles



Everyone is different. Different shapes. Different sizes. Different needs. That's why at Danmar we customize our products for each individual. Seating and positioning devices which fit to a T. Helmets custom-designed for pony tails or buzz cuts. Swim aides so secure you're a fish in the water. You have a special need. We have a special product, one custom made for your smile.

Website: www.danmarproducts.com
Phone: (800) 783-1998

DANMAR

Special Products for special needs since 1968.

Danmar Products, Inc., 221 Jackson Industrial Drive, Ann Arbor, MI 48103 USA

Circle #31 or visit www.eparent.com/adinfo

1193

organizational spotlight

The Tuberous Sclerosis Alliance

By Marybeth Leongini

MISSION STATEMENT

The Tuberous Sclerosis Alliance is dedicated to finding a cure for tuberous sclerosis while improving the lives of those affected.

HISTORY

Founded in 1974, the Tuberous Sclerosis Alliance (TS Alliance) was established by four mothers who sought to provide fellowship, generate awareness and provide hope to those that share the common bond of tuberous sclerosis complex (TSC). TSC is a genetic disorder characterized by seizures and tumor growth in vital organs.

In addition to serving as an advocate and promoting research on TSC, the TS Alliance serves as a clearinghouse for families and physicians seeking current and comprehensive information on TSC.

WHAT IS TUBEROUS SCLEROSIS COMPLEX?

First described in the 1880s, tuberous sclerosis complex (TSC), also known as Bourneville's disease, is a genetic disorder commonly characterized by seizures and tumor growth in vital organs such as the brain, heart, kidneys, lungs and skin. The name "tuberous sclerosis" comes from the characteristic tuber or root-like growths in the brain, which calcify with age and become hard or sclerotic. In most individuals, the disease affects only some of the vital organs. The disorder affects some people severely, while others are so mildly affected that it often goes misdiagnosed or undiagnosed. Many people with TSC experience developmental delays, mental retardation or autism. Many TSC manifestations also develop later in life. Some individuals who are mildly affected by TSC lead active and productive lives, but it is important to realize that a diagnosis of TSC can mean life-long complications and individuals should receive continuous follow-up care.

Because of advances in testing methods, the number of diagnosed individuals has risen dramatically in recent years as people with less-severe manifestations of TSC are identified. Population-based studies indicate that TSC has an incidence of one in 6,000 live births. It is estimated that approximately 50,000 Americans and 1 million individuals worldwide have TSC. There are also many undiagnosed cases of the disorder as a result of the obscurity of the disease and the mild symptoms some people have. TSC is as common as Lou Gehrig's disease (ALS), but still virtually unknown by the general population.

A LEGACY OF SERVICE INFORMATION

Because TSC is often difficult to diagnose and proper management of TSC is essential to optimum health, the TS Alliance continues to focus on educating medical professionals through medical conferences, outreach and awareness efforts and alliances with a number of patient advocacy programs.

By producing informative fact sheets, brochures, and other resources, the TS Alliance strives to educate healthcare providers on identification, diagnosis and treatment protocols. *Perspective*, the organization's quarterly newsletter, offers families current news about the Alliance along with research updates, government relations actions and special events. A constantly evolving Web site (http://www.tsalliance.org) serves as the primary source of information to a worldwide community of doctors and families seeking up-to-date information about TSC, while also serving as a networking tool for families to share support and information through various list-serves.

One of the most recent initiatives, The Life Stages Guide, was created to provide detailed information to assist individuals with disabilities, their family members and others in coping with the day-to-day challenges of life with a disability. Raising a child with special needs is often likened to a journey or voyage. Using this analogy, The Life Stages Guide addresses the four stages of life:

- **Starting the Voyage**—The Early Years (ages 0-5)
- **Staying the Course**—The School Years (ages 6-13)
- **All Hands on Deck**—The Teen & Young Adult Years (ages 14-21)
- **Setting Sail**—The Adult Years (ages 21 and above)

Locating information on programs and services for individuals with a disability is a daunting task. The goal of The Life Stages Guide program is to provide a comprehensive source for educational, social, financial and vocational information. Setting Sail - The Adult Years section of the guide is now available and work is currently underway on All Hands on Deck - The Teen and Young Adult Years.

SUPPORT

An extensive network of dedicated volunteers across the country donates its time, talent and energy to support the Volunteer Outreach Program. Our Volunteer Outreach Program includes the TS Alliance Support Network, Matching Program, National Outreach and Awareness Campaign, community fund-raising events and Community Alliances. This program enables volunteers to create awareness of TSC in their communities, to establish peer connections and to participate in fund-raising events and campaigns.

The TS Alliance Support Network is an organized partnership of individuals whose lives have been affected by TSC. This national network of volunteers provides individual, family and caregiver support and organizes community gatherings and support groups on the local level. A recently revised initiative, the TS Alliance Matching Program is designed to match individuals and/or families throughout the country who are experiencing similar challenges. The matching program provides people with the peer support that may not be available in their communities.

Community Alliances are local volunteer committees that empower and engage volunteers in local support for individuals and families and in community fund raising. They also promote outreach and awareness campaigns to raise the visibility of the disorder to the medical community, community agencies and school systems.

REACHING OUT THROUGH THE HALLS OF CONGRESS

In the year 2000, the Tuberous Sclerosis Alliance launched an aggressive government relations program.

Last year the first fruits of this labor were seen with the establishment of The Tuberous Sclerosis Research Program in the Congressionally Directed Medical Research Program (CDMRP) in the Department of Defense. The Tuberous

continued on page 92

Specially trained dentists and custom facilities are desperately needed in New Jersey to treat individuals with physical disabilities, such as cerebral palsy, muscular dystrophy, spina bifida, and Lesch-Nyhan disease.

The Delta Dental Plan of New Jersey Foundation is partnering with Matheny School and Hospital to create a new, state-of-the-art dental facility to improve access to dental care. This initiative is part of Delta Dental's mission to promote and assist educational projects devoted to the enhancement of dental health and research programs designed to increase public awareness of the general benefits of good health, and to improve dental health through the science of dentistry. For more information about the Matheny School and Hospital dental facility, call (908) 234-0011, ext. 231.

Dr. Gerald Sydell
Chairman, Delta Dental Plan of New Jersey and
Vice President, Delta Dental Plan of New Jersey Foundation, Inc.

Matheny
School and Hospital
www.matheny.org

DELTA DENTAL
Delta Dental Plan of New Jersey Foundation, Inc.
www.deltadentalnj.com

Circle #56 or visit www.eparent.com/adinfo

The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW

- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made In U.S.A.

Circle #40 or visit www.eparent.com/adinfo

continued from page 91

Sclerosis Complex Research Program was added to the CDMRP in 2002 at the funding level of $1 million.

RECOGNIZING RESEARCH IS OUR FUTURE

Research into the genetics of TSC may shed additional light on the causes of other conditions. The Center Without Walls (CWW) was created to enable researchers to share information and resources, thus expediting research results and their translation to improved clinical care of individuals with TSC.

HOW DOES ONE DEVELOP TSC?

TSC is transmitted either through genetic inheritance or as a spontaneous genetic mutation. Children have a 50 percent chance of inheriting it if one of their parents has the condition. Right now, only one-third of TSC cases are known to be inherited, while the other two-thirds are believed to be a result of spontaneous mutation. What causes these mutations is still a mystery.

WILL A CHILD BE MILDLY AFFECTED IF THE PARENT IS?

People with mild cases of TSC can have a child who is more severely affected. In fact, some people are so mildly affected that they may go undiagnosed until their more severely affected child receives a diagnosis of TSC.

WHAT CAUSES TSC?

Two genes have been identified as causing TSC, but only one of the genes needs to be affected for TSC to be present. The TSC1 gene is located on chromosome 9, the same chromosome that carries the gene that determines blood type. The TSC2 gene is located on chromosome 16. TSC occurs when an individual has a mutation in either the TSC1 or the TSC2 genes. The mutation can be inherited from one parent or can be a new mutation (sporadic event) that developed within the person. Recent studies have shown that in familial cases of TSC (when there are two or more people with TSC in the family), about 50 percent of the families have a mutation in TSC1, and the other half contain a mutation in TSC2. Research has also shown that in sporadic cases of TSC (where there is no prior family history of TSC), more of the individuals have a mutation in the TSC2 gene than in the TSC1 gene.

Special Bikes for Special People

Haverich

A wide choice of
bikes, colors and
adaptive equipment
for people with
special needs.

165 Martell Court, Keene, NH 03431
Tel: 603-358-0438 • Fax: 603-358-0453
www.haverich.com

Circle #43 or visit www.eparent.com/adinfo

HOW IS TSC DIAGNOSED?

Until recently, diagnosis of TSC was based on clinical findings. Some of the tests used to assist in making the diagnosis are a brain MRI or CT scan, renal ultrasound, echocardiogram, EKG, eye exam and a Wood's Lamp evaluation of the skin. In September of 2002, the TS Alliance announced the transfer of a diagnostic genetic test for TSC from a TS Alliance-funded research environment to a fee-for-service clinical laboratory, Athena Diagnostics. As a result of this transition, DNA testing for TSC will be more widely available to individuals with TSC, their families and also to their physicians.

WHAT IS THE NORMAL LIFE EXPECTANCY OF AN INDIVIDUAL WITH TSC?

Most people with TSC will live a normal lifespan. There can be complications in some organs such as the kidneys and brain that can lead to severe difficulties and even death if left untreated. To reduce these dangers, individuals with TSC should be monitored by their physicians throughout their lives for potential complications .

PROFILES OF COURAGE

Anna Enstrom is a 27-year-old with tuberous sclerosis complex. Diagnosed in 1978, Anna has severe cognitive and physical disabilities. She has continued to surpass the life expectations forecast by medical doctors and other experts, and she is an inspiration of strength to many people.

Sophia Mayrsohn is almost 5 years old. Her parents learned of her diagnosis when she was just 10 weeks old. Sophia has many hamartomas (tubers) in her brain and has intractable epilepsy, despite the fact that she has undergone epilepsy surgery twice. Through all of the pain and suffering Sophia's family has become much stronger. In the words of her mother Kathy, "Living with TSC has made me a better person. I don't take things for granted anymore. My daughter Sophia is my biggest hero. She has suffered so much, yet continues through all of this with a huge smile on her face."

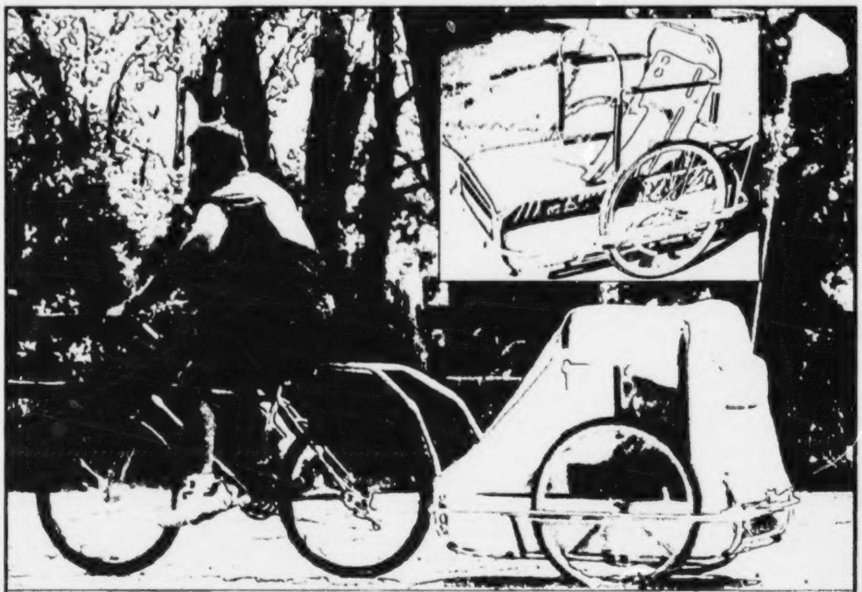
Cade Scott celebrated his 11th birthday on August 1, 2002. He was diagnosed with TSC when he was just 7-and-a-half months old and continues to struggle with the many issues that this condition brings. His mother Nancy clearly remembers the very moment—the where, the when and the how—of hearing the words "tuberous sclerosis" for the first time. "...the fear of the unknown that overtook us that day and the uncontrollable spin our lives took in what had seemed a controlled world only moments before. Within a week we became connected with the TS Alliance and felt fortunate to have found them so quickly. Our relationship with the organization began to grow; the more we became involved the more benefits we experienced. As we gained knowledge of TSC and our support network of friends grew we felt in control of our lives again," says Nancy.

Robbie Seymour is a 5-year-old with TSC. When Robbie was younger, the prognosis for his ever being able to talk in full sentences was poor. Today, thanks to his self-motivation, his devoted and loving parents, and some very caring speech therapists, the hope that he would one day speak has become a reality. Robbie continually exhibits strength, intelligence and courage that all who know him are sure will continue with Robbie on his journey through life.

SINCE THERE IS NO CURE, WHAT CAN BE DONE?

Early intervention is helping to diminish developmental delays, and advances in research bring new and improved therapeutic options. Surgery to remove tumors now helps to preserve the function of affected organs. With improved technology, we can start to pinpoint the exact portions of the brain undergoing seizures, and create new therapies to help control seizures. Each day brings us closer to finding improved treatments. People with TSC can stay informed about the advances that are made by becoming a Tuberous Sclerosis Alliance member and receiving information and updates. Call toll-free at (800) 225-6872; send an e-mail to info@tsalliance.org; or send a letter to 801 Roeder Road, Suite 750, Silver Spring, MD 20910 for more information or to become a member. **EP**

Marybeth Leongini joined the Tuberous Sclerosis Alliance as director of communications in May of 2002. Her responsibilities include media relations, publication management and web development. She received her bachelor's degree from Belmont Abbey College in North Carolina and completed her graduate studies at the University of South Carolina's School of Journalism and Mass Communications.



Enjoy the out-of-doors together with a

CycleTote® Bicycle Trailer Running Stroller

1-800-747-2407 www.cycletote.com

Satisfaction Guarantee/Lifetime Warranty

visit www.eparent.com/adinfo

AUTISM RISING:

Delivering Services without Draining Parents and School Systems

The increase in children with autism or autistic-like disorders—no matter whose statistics or definitions you use—appears real and here to stay. At the same time, parents of children with autism find themselves at odds with their child's school as to the best way of treating and helping them. For their sake, we hope that parents, educators, researchers, and government officials can be allies and not adversaries.

Autism is a neurodevelopmental disorder defined by developmental delays and maladaptive behaviors. The 2000 Diagnostic and Statistical Manual of the American Psychiatric Association characterizes autism by marked impairments in social interaction, delays and/or disorders in communication, and restrictive or repetitive patterns of interests or behaviors (e.g., stereotypical behaviors). Autism is also a disability category covered by the Individuals with Disabilities Education Act (IDEA). The early onset, severe behavioral challenges, and poor long-term prognosis combine to make this one of the most stressful disorders for families.

In recent years there has been a striking increase in the number of children diagnosed with autism. Using the Department of Developmental Services database in California, for example, Lisa Croen and her colleagues just reported that prevalence rates from 1987 to 1994 increased from 5.8 to 14.9 per 10,000.

Peter Sturmey of Queens College, and Vernon James of the Texas Center for Autism Research and Treatment, also reported high prevalence rates (16 per 10,000) using data from the Texas education system in the year 2000. However, as in other reports, the number was higher for younger children (grades 1 through 3) at 22 per 10,000. In his 2002 presentation at the Gatlinburg Conference for Research on Mental Retardation and Developmental Disabilities, Paul Shattuck of the University of Wisconsin-Madison provided detailed statistics on national trends in the prevalence of autism in public schools. He reported that from 1994 to 2000, the average annual increase was 21%!

Bigger Pool or Better Diagnosis?

Certainly, the numbers cited above are compelling, and the media has made headlines of them. One reason for "autism rising", is that the diagnostic criteria and definitions have changed. Many children who do not manifest the "full syndrome" of autism still bear the label, because they fall along an "autism spectrum."

Related disorders, hardly diagnosed before the last 15 years, are Asperger's disorder and Pervasive Developmental Disorder. In fact, the prevalence figures I cited would be even higher if the full range or spectrum of autism-related conditions were included. This expansion of what we consider "autism" results in more frequent use of the label, more research focus on autism spectrum disorders, and a greater likelihood that the disorder will be identified by parents, physicians, psychologists and school professionals. Whether there is also increased environmental or genetic risk for autism today is unclear, but the demand for services, particularly early intervention, is real indeed.

Critical Diagnostic and Treatment Timing

Autism is usually diagnosed by the time an affected child is 2 or 3 years old and there is convincing evidence that the next two or three years provide a window wherein intervention must be carried out to be maximally successful.

In a recent essay on autism in the journal Science (2001), Erik Stokstad stated that "the treatment with the most scientific support is behavioral training." This consists of intensive therapy, often up to 40 hours a week, delivered in the child's home setting. It likely results in children who "follow instructions better, learn how to imitate, and have enriched vocabularies" (p. 37).

continued on page 95

Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, where she has been a researcher for 20 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of mental retardation, dual diagnosis and the transition to adulthood. Dr. Blacher has developed **Research Reflections** as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to **Research Reflections** and any suggestions you might have. Send e-mail to: jan.blacher@ucr.edu.

The empirical support for this model stems from a seminal 1987 research paper by Ivar Lovaas, of UCLA. Children who receive this intensive intervention often transition into preschools or kindergartens with typical peers who provide more language and social exchanges opportunities than would be available in a classroom containing only children with autism or related disorders.The "rub" in this is that the treatment costs thousand of dollars each month ($40,000 a year and up). Few families are able to pay this amount and few school systems are willing.

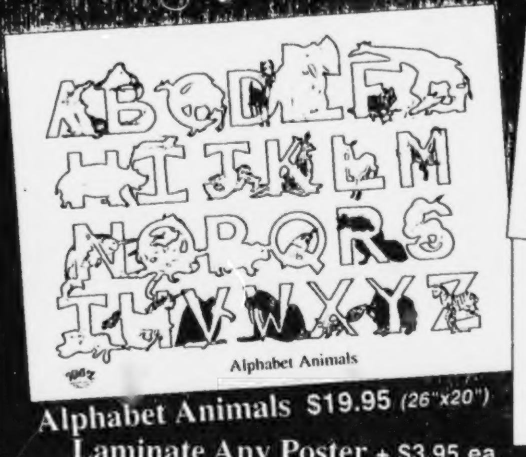
It is clear that neither parents nor school officials will be able to go it alone much longer if the growing numbers of children with autism diagnoses are to be served.

School administrators balk at the costs, focusing on the annual budget over the long-term economic gains if even a modest percentage of children with autism become independent of the service delivery system and gainfully employed adults. School districts characteristically offer scientifically indefensible strategies in a self-contained classroom for children with autism and other, unrelated disorders. To further frustrate already stressed and scared parents, teachers and their aides are often woefully ignorant of, and/or inexperienced in the use of, behavior analytic techniques.

What has ensued is a flurry of administrative hearings, sometimes advanced to court, whereby parents demand a home program for their child, perhaps supplemented by placement in a class containing typical peers. (To date, no one has tallied the millions of dollars in legal

continued on page 96

Learning by Association! *The Art of the Alphabet!*



The Bunnies

Alphabet Animals $19.95 (26"x20")
Laminate Any Poster + $3.95 ea.
100% SATISFACTION GUARANTEED!

Bears or Bunnies
$9.95 ea. (22"x18")

Kid's #1®

Help your child know the alphabet before kindergarten!
Learning by Association
Copyright 2002 • All Rights Reserved
Kid's # 1, Inc. Minneapolis, Minnesota

Receive FREE *Bears* or *Bunnies* poster *with* purchase of *each Alphabet* poster!
When purchasing *any two* or more posters, *receive* **$1.00 DISCOUNT** each poster!
Order 24 hours a day/7 days a week
1-888-844-5200 or www.kids-1.com
VISA • MASTERCARD • AMEX • DISCOVER
Add $7.95 s&h • Minnesota residents add sales tax
INQUIRE FOR VOLUME DISCOUNTS OR WHOLESALE SC AGN005

Circle #49 or visit www.eparent.com/adinfo

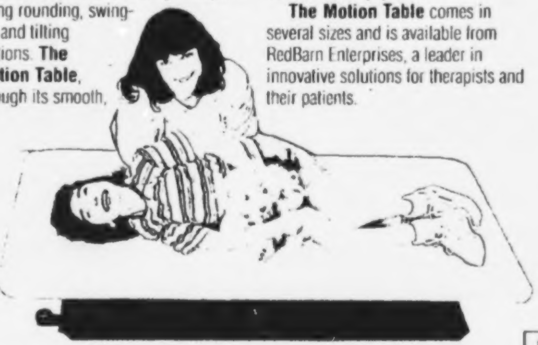
Get More Out of Vestibular Stimulation with The Motion Table

The Motion Table enables therapists to deliver the value of vestibular motion to their patients without the need for constant hands-on intervention.

Most stimulation equipment available today reduces the therapeutic effect of *horizontal motion* by incorporating rounding, swinging and tilting motions. **The Motion Table**, through its smooth, "vibra glide" movement provides a steady, uniform stimulation that can help "level out" extremes in patients' behavior.

And, since **The Motion Table** is motorized, patients can be stimulated for longer periods than is possible with manual equipment.

The Motion Table comes in several sizes and is available from RedBarn Enterprises, a leader in innovative solutions for therapists and their patients.



The Motion Table reduces...
- *Hypersensitivity*
- *Self-abuse*
- *Abnormal Muscle Tone*
- *Constipation*
- *Pulmonary Congestion*

The Motion Table increases...
- *Concentration*
- *Attentiveness*
- *Calmness*
- *Body Awareness*
- *Postural Control and Balance*

RedBarn ENTERPRISES

Try The Motion Table AT NO RISK for 30 days.
Try it for a month. If you're not completely satisfied, just send it back for a complete refund.

For a copy of a just-released Technical Evaluation of The Motion Table or additional product information, call us at 1-800-577-1317, or visit us on the Worldwide Web at www.redbarn-enter.com.

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.redbarn-enter.com**

Circle #64 or visit www.eparent.com/adinfo

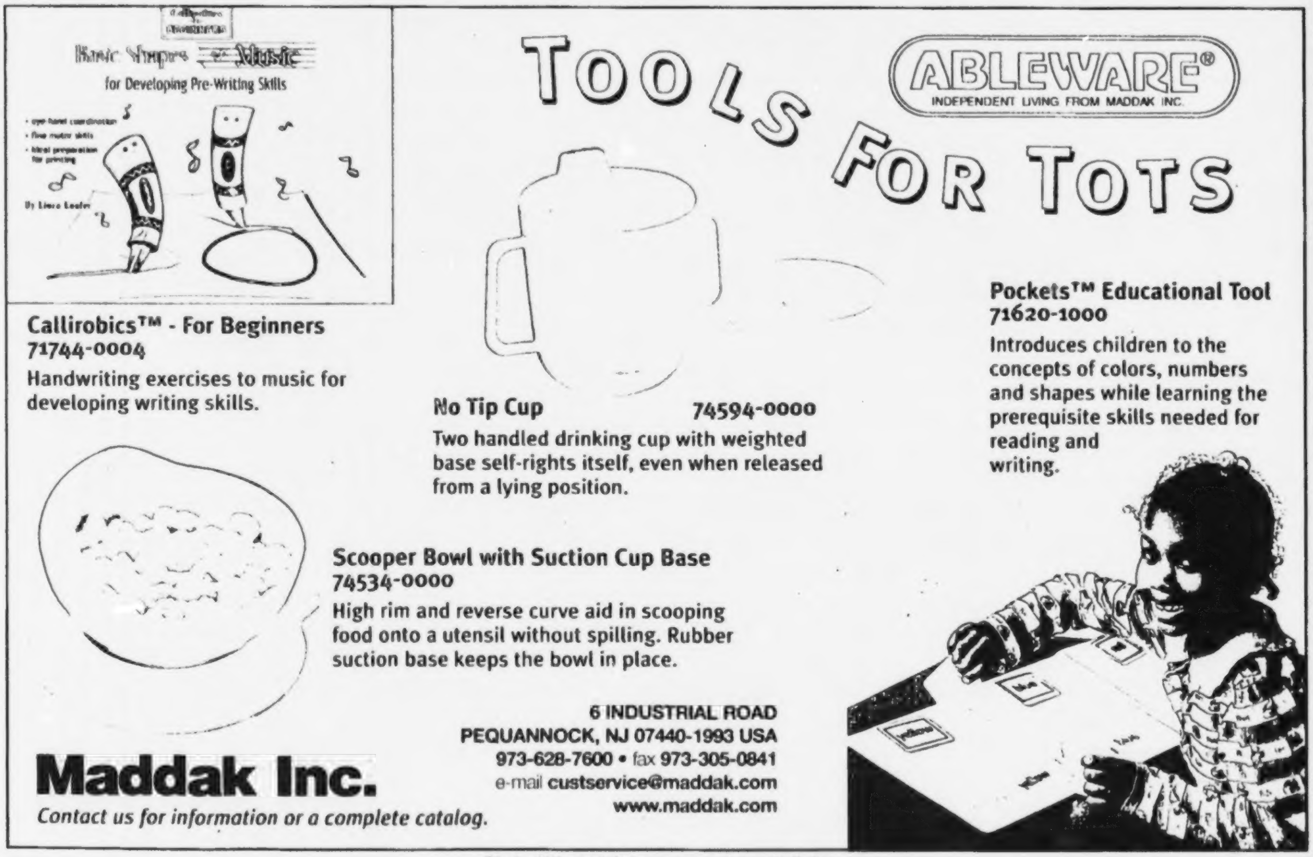
To further frustrate already stressed and scared parents, teachers and their aides are often woefully ignorant of, and/or inexperienced in the use of, behavior analytic techniques.

continued from page 95

costs spent by school districts in fighting parents—monies that could have funded programs for many children). There are dilemmas here to be sure. Parents cannot be faulted for desiring an empirically valid treatment for their child—one that must be delivered early on during the "window of opportunity" for learning. Yet school resistance, requiring family legal counsel, limits eventual access to more affluent families. From the school district's perspective, there is a crisis in both available funding and in teacher preparation.

There is a need to offset the long-term costs to the nation of providing appropriate educational treatment for children with autism. I see four specific actions that can be taken that may alleviate some of the financial and emotional drain that serving young children with autism is causing:

- ***More support for research on treatment effectiveness.*** While research supports the effectiveness of applied behavior analysis, it is essential to "dismantle" effective treatment packages to see which components are essential to their success. We need to determine the ideal number of hours of discrete trial training and how this approach is best combined with other approaches (e.g. incidental teaching,


Basic Shapes to Music
for Developing Pre-Writing Skills
TOOLS FOR TOTS
ABLEWARE®
INDEPENDENT LIVING FROM MADDAK INC.

Callirobics™ - For Beginners
71744-0004
Handwriting exercises to music for developing writing skills.

No Tip Cup 74594-0000
Two handled drinking cup with weighted base self-rights itself, even when released from a lying position.

Pockets™ Educational Tool
71620-1000
Introduces children to the concepts of colors, numbers and shapes while learning the prerequisite skills needed for reading and writing.

Scooper Bowl with Suction Cup Base
74534-0000
High rim and reverse curve aid in scooping food onto a utensil without spilling. Rubber suction base keeps the bowl in place.

6 INDUSTRIAL ROAD
PEQUANNOCK, NJ 07440-1993 USA
973-628-7600 • fax 973-305-0841
e-mail custservice@maddak.com
www.maddak.com

Maddak Inc.
Contact us for information or a complete catalog.

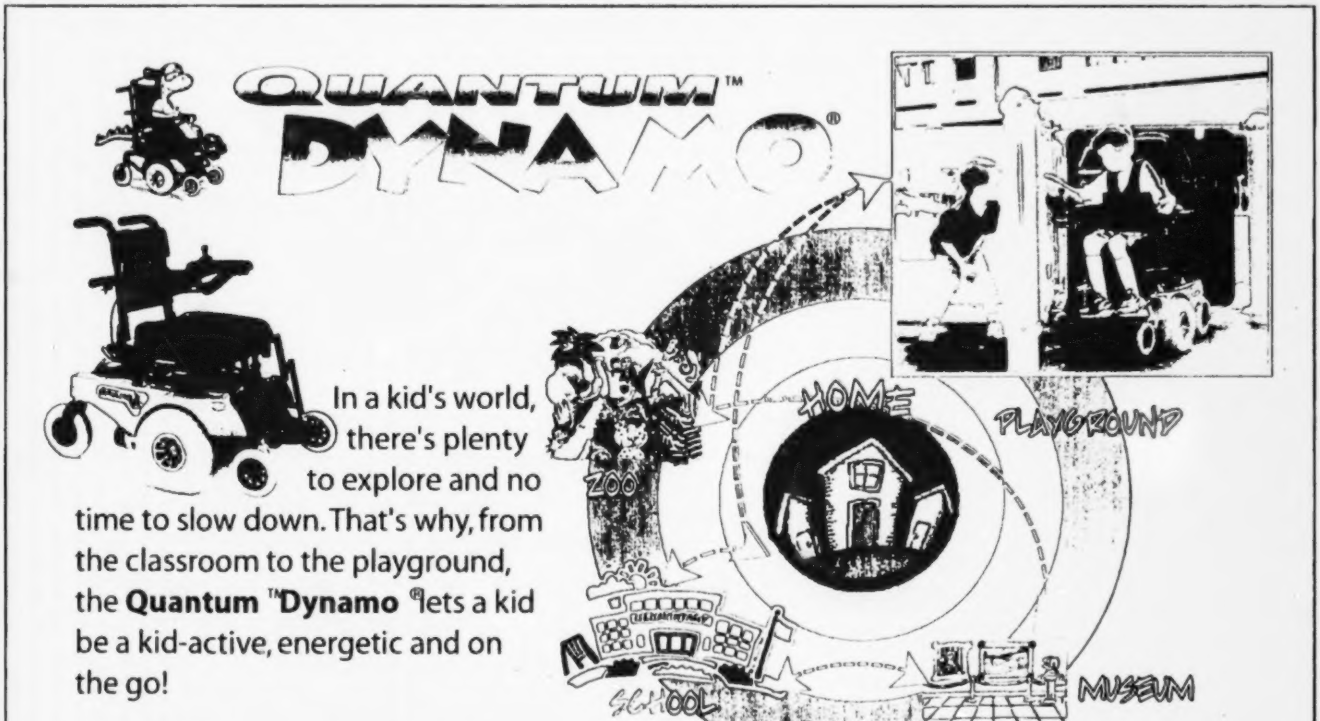
Circle #55 or visit www.eparent.com/adinfo

peer interactions). We need comparisons of service delivery settings (e.g. home vs. school). We need data on the long-term effects of interventions, on their impact on families, and on how they can be realistically incorporated into non-research settings. Such research requires a major commitment by governmental agencies, such as the $38.8 million autism clinic and research center that California is building at UC Davis.

- ***More targeted assistance for professional development.*** Special funding allocations, perhaps in the form of personnel preparation grants, need to be made to universities and colleges for the purpose of training teachers who will specialize in autism. An applied behavior analysis component is essential. School districts could also receive some financial incentive for sending teachers to such programs.

- ***School district willingness to to set up state-of-the-art programs to serve young children with autism:*** I have personally observed many programs that were described by school officials as model programs, but then fell far short in practice. Rarely are the teachers and assistants appropriately trained behaviorally, and rarely is the service delivered intensively, with data collected for the purpose of demonstrating any kind of long-term durable effect. With the increased autism census, it is now more possible, and more necessary, for school systems to establish "best practice" centers.

- ***Parents need to be partners in the autism intervention:*** Parents should have a key role in early intervention. Just as parents of a child with diabetes or PKU have to alter and monitor their child's diet, parents of a young child with autism need to carry some of the responsibility of learning behavioral techniques themselves, of home teaching, and of providing "real world" opportunities for the child to generalize skills and language learned in other settings. EP


QUANTUM™ DYNAMO®

In a kid's world, there's plenty to explore and no time to slow down. That's why, from the classroom to the playground, the **Quantum™ Dynamo®** lets a kid be a kid-active, energetic and on the go!

QUANTUM™ REHAB
LEAPING AHEAD WITH MORE ADVANCED REHAB PRODUCTS AND SERVICES

1-866-800-2002
182 Susquehanna Ave., Exeter, PA 18643
www.quantumrehab.com

Circle #62 or visit www.eparent.com/adinfo

Getting information from EP advertisers is MUCH FASTER ONLINE!

It's as easy as a click of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE
Information from Advertisers
CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in Exceptional Parent.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.

Be sure to tell them you saw their ad in Exceptional Parent!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
17	ABILITIES EXPO	101
23	ADAPTIVEMALL.COM	113
18	AD-AS LLC	61
19	ANDERSON SCHOOL	79
20	ANNANDALE VILLAGE	84
21	ANNE CARLSEN SCHOOL	87
24	BODYPOINT DESIGNS, INC.	87
25	CAMPHILL SPECIAL SCHOOL	110
26	COLUMBIA MEDICAL	9
27	CONNETQUOT WEST	103
28	CONSUMER CARE PRODUCTS, INC	83
29	CROTCHED MOUNTAIN	81
30	CYBERONICS, INC.	10-12
	CYCLETOTE CORP.	93
31	DANMAR PRODUCTS	89
32	DURALIFE, INC	83
33	DURALINE MEDICAL PRODUCTS	70
34	EDEN FOODS, INC.	13
35	ENGLISH AVE INDUSTRIES	67
200	EP LIBRARY BOOK CLUB	85
200	EP LIBRARY PAGES	106-107
45	EP NEWBORN SCREENING DVD	88
199	EP SUBSCRIPTION CARDS	17-18
36	EQUIPMENT SHOP	104
37	EVERGREEN CENTER	110
38	FORD MOBILITY	C3
39	FREEDOM MOTORS USA	75
40	GLOBAL POWER SYSTEMS INC	91
41	H.D.I.S.	54
42	HARD MANUFACTURING	16
43	HAVERICH ORTHO-SPORT, INC.	92
22	HEARTSPRING	53
44	HMS SCHOOL	66
	HOUSE AD	98
78	IBM SPECIAL NEEDS SYSTEM	C2
46	INNOVATIVE PRODUCTS	48
47	INTERACTIVE METRONOME	47
48	KENNEDY KRIEGER	31
49	KIDS #1, INC.	95
50	KIMBERLY CLARK CORP.	41
51	LAWYERS, INC.	71
52	LEARNING EXPRESS	34
53	LIBERTY MOTOR COMPANY INC	33
54	LITIGATORS, INC.	25
55	MADDAK INC.	96
56	MATHENY SCHOOL & HOSPITAL	91
57	MELMARK	59, 104
58	MERRILL LYNCH	55
59	MIDWEST MOBILITY AND DESIGN	48
60	OCEAN HYPERBARIC CENTER	77
61	OTTO BOCK	7
62	PRIDE MOBILITY	97
63	REAL DESIGN	82
64	RED BARN ENTERPRISES	95
[illegible]	ROSS LABORATORIES	73
66	SAMMONS-PRESTON	23
67	SIGMA TAU	1-2
68	SNUG SEAT INC	5
69	STEWART HOME SCHOOL	103
70	THE BABY JOGGER COMPANY	66
71	THE CENTER FOR DISCOVERY	49
72	THE NYU HOSP FOR JOINT DISEASE CTR	60
73	ULTRAFLEX SYSTEMS, INC.	70
74	VAIL PRODUCTS	C4
76	VERIZON	3
75	WOODBURY PRODUCTS	83
77	WORLD CONGRESS	20

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106

EP

has the information an "Exceptional Parent" like you needs

EP

Exceptional Parent

Subscribe on our website: www.eparent.com and save $5.00

For telephone orders call:

877-372-7368

To start your subscription to EP today, fill out the card near the front of this magazine or log on to

www.eparent.com

EP MAGAZINE Free product & service information order card*

OCTOBER 2002

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______________________

Address ______________________

City ______________ State ______ Zip ______

Phone ______________ Fax ______________

E-mail ______________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? 1☐ Yes 2☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3☐ Yes 4☐ No

If Yes, are you a: 5☐ Physician 6☐ RN 7☐ Physical Therapist
8☐ Occupational Therapist 9☐ Speech Pathologist; Audiologist
10☐ Other (please indicate) ______________

D. Are you an EDUCATOR? 11☐ Yes 12☐ No

If Yes, are you a: 13☐ Other (please indicate) ______________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? 14☐ Yes 15☐ No

If yes, please explain ______________

F. Do you use EP to find a product or service? 16☐ Yes 17☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

***CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: March 31, 2003**

BOCT2

EP MAGAZINE Free product & service information order card*

OCTOBER 2002

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______________________

Address ______________________

City ______________ State ______ Zip ______

Phone ______________ Fax ______________

E-mail ______________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? 1☐ Yes 2☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3☐ Yes 4☐ No

If Yes, are you a: 5☐ Physician 6☐ RN 7☐ Physical Therapist
8☐ Occupational Therapist 9☐ Speech Pathologist; Audiologist
10☐ Other (please indicate) ______________

D. Are you an EDUCATOR? 11☐ Yes 12☐ No

If Yes, are you a: 13☐ Other (please indicate) ______________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? 14☐ Yes 15☐ No

If yes, please explain ______________

F. Do you use EP to find a product or service? 16☐ Yes 17☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

***CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: March 31, 2003**

BOCT2

To start your subscription to EP today, fill out the card near the front of this magazine or log on to
www.eparent.com

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

1204

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others wh are providing a richer life for themselves and for their children.

Exceptional Parent's MISSION

IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS
Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

abilities EXPO

Northern California

San Mateo County

Expo Center

November 22-24

Education and *Equipment* to *Empower.*

Come **sample products** and **talk one-on-one** with service providers. As our guest you can attend **complimentary educational workshops** on everything from better sex to better jobs. Or perhaps you would like to see the power of new technologies in our **Access Ability Pavilion**. There are many options for you at **Abilities Expo.**

For more information please call (800) 385-3085 or (218) 723-9130 outside of the USA.
www.abilitiesexpo.com

abilities EXPO

PRESENT THIS COUPON FOR FREE ADMISSION

[ADMIT ONE]

Bring coupon to any **2002 Abilities Expo** and save the $5 on-site registration fee.
Coupon must be filled out to be valid and may be photocopied for additional registrants.

NAME: ______

ADDRESS: ______

CITY: ______ STATE: ______ ZIP: ______

For information call:
(800) 385-3085
(218) 723-9130 (outside USA)

Produced and Managed by:

ADVANSTAR COMMUNICATIONS

All events are wheelchair accessible.

1205

10

© 2002 Advanstar Communications Inc. All rights reserved.

Circle #17 or visit www.eparent.com/adinfo

Prenatal Screening vs Newborn Screening

By Frank Manginello, M.D.

Director of Neonatology and Medical Director, Center for Child Development, The Valley Hospital, Ridgewood, NJ

Q What is the difference between prenatal screening and newborn screening? How do I know when I need one, the other, or both? Why is screening so important?

A Both prenatal screening and newborn screening have a similar goal: to identify whether the baby has any health problems. Parents can certainly benefit from both prenatal and newborn screening, as each provides different types of information about a baby's health. The most significant difference between the two types of testing is actually a matter of timing. Prenatal testing is performed on the mother during pregnancy; newborn screening is performed after the baby is born.

PRENATAL TESTS

Prenatal tests that you may have heard of include ultrasound, amniocentesis and maternal blood tests. This form of testing also tends to be a more targeted form of testing. In other words, the types of tests performed are based on the mother's age and medical history, family history of certain medical conditions, or other concerns specific to each baby or each pregnancy. As a matter of fact, screening and genetic counseling may also be offered to a couple before conception, under certain circumstances. Speak with your obstetrician to learn more about prenatal testing and the types of tests he or she recommends for you and your baby.

NEWBORN SCREENING

Newborn screening is a more general type of testing that is performed the same way on every baby and is not targeted to specific issues or concerns. The actual procedure is quite simple. A small sample of blood is obtained by pricking a baby's heel, usually on the second day of life. The blood then dries on absorbent paper and is sent to a laboratory for analysis using sophisticated technology, such as tandem mass spectrometry. At my hospital, abnormal results are provided to both the hospital and the baby's pediatrician within 24 to 48 hours of birth.

Newborn screening also offers a simple, inexpensive way of determining whether a baby has a metabolic disorder that, if left untreated, could result in permanent neurological or developmental damage, even death. Metabolic disorders, which affect at least 1 in 1,000 babies born in the United States each year, are inherited genetic disorders that interfere with the body's ability to break down fats, sugars, or proteins in food.

Most babies born with these disorders look and act perfectly healthy at first. Without newborn screening, the problem is not discovered until the child develops symptoms, which is often too late to prevent permanent damage. While these diseases cannot be completely cured, they can usually be treated, reducing—and in some cases eliminating—the risks to the child. Treatment is often as simple as monitoring or removing the food that cannot be metabolized from the child's diet.

One of the more common of the metabolic disorders, and one for which all babies are now routinely tested, is phenylketonuria (PKU), characterized by the inability to process the amino acid phenylalinine, which is commonly found in protein-rich foods. Another is MCAD (medium chain acyl-CoA dehydrogenase deficiency), a disorder that affects the ability to process fat and may be responsible for up to 10 percent of deaths attributed to sudden infant death syndrome.

Ask the Doctor addresses issues of concern to our readers. Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products. Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com.

Others are maple syrup urine disease, a disorder in which several amino acids can not be metabolized properly; cystic fibrosis, the most common inherited metabolic disease among Caucasians; galactosemia, an inability to properly digest galactose, a type of sugar found in milk; and glutaric acidemia (Type I), a disorder of amino acid metabolism characterized by the build-up of glutaric acid.

EARLY IDENTIFICATION IS IMPORTANT

But early identification is the key. I am an avid supporter of newborn screening, particularly universal newborn screening, meaning all newborns should receive all available tests. Unfortunately, the rules in each state vary widely and currently many babies receive only very limited testing. (see EP Magazine, August, 2002 for a listing by state).

In fact, many states mandate evaluation for only four to six disorders. Some states, including New Jersey, where I live and practice, have adopted expanded newborn screening, For example, New Jersey recently expanded its list of mandatory tests from 4 to 14 metabolic disorders. I do not think that goes far enough. Right now, technology is available to test for more than 50 potentially treatable metabolic disorders. At The Valley Hospital in Ridgewood, we recently made the decision to contract with a private laboratory to test every single baby born at the hospital for these more than 50 disorders.

We also offer universal hearing tests. In most cases, the tests serve to reassure parents that their baby is healthy. And in those cases in which problems are discovered, parents can also take comfort in knowing that appropriate treatment was initiated days after birth, giving their baby the best possible start in life.

The good news is that efforts are underway to close the wide disparity in newborn screening guidelines among the states. And I am hopeful that universal newborn screening will become a reality in the not-so-distant future. But in the meantime, I urge you and other expectant parents to take matters into your own hands. You are, after all, your baby's best advocate.

First, find out what screening tests your local hospital routinely performs. If you are lucky, you will find a hospital in your area that offers screening for the full range of metabolic disorders. If not, talk to your obstetrician and pediatrician—they may be able to assist in making arrangements with a private lab for expanded screening. Or you can call a private lab directly to make arrangements to have your baby screened. EP

Connetquot West, Inc.
Health Care Products

Pressure Management
Nutritional/Enteral
Specialty Seating
Bathroom Safety
Personal Care
Incontinence
Ambulatory
Respiratory
Urological
Beds/Lifts
Skin Care
Mobility

This month's
FREE SAMPLE FEATURE
Resource Just for Kids
CALL FOR YOURS!

HOME DELIVERY!

Quality for You. Quality for Life.

Toll-Free: 866-588-3888

Fax Toll Free: 866-588-3337

711-3 Koehler Avenue ○ Ronkonkoma ○ New York ○ 11779
Email: connetquot@aol.com

Circle #27 or visit www.eparent.com/adinfo

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #69 or visit www.eparent.com/adinfo

THE MELMARK SCHOOL
2600 Wayland Road, Berwyn, PA 19312 ◆ 1-888-MELMARK ◆ Fax (610) 353-4956 ◆ www.melmark.org

Our approved private day and boarding school serves children ages 5 - 21 who have:

- Autism/Pervasive Developmental Disorders/Asperger Syndrome
- Acquired Brain Injuries
- Cerebral Palsy
- Mental Retardation
- Neurological Disorders

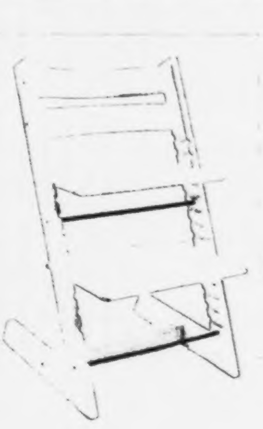
Situated on an 80-acre country campus, Melmark's goal is to maximize independence through "best practices" in Applied Behavior Analysis, functional curriculums, vocational training and collaborative services.

We Offer Your Child:

- Low Student/Teacher Ratios
- Applied Behavior Analysis
- Functional Communication Skills
- Adaptive Physical Education, Aquatics, and Therapeutic Horsemanship
- Physical, Speech and Occupational Therapy
- On-Site Physicians and 24-Hour Nursing
- Psychological and Family Support

To arrange a personal visit, request a brochure or video, contact Peter McGuinness, Director of Admissions, at 1-888-MELMARK or email admissions@melmark.org

Circle #57 or visit www.eparent.com/adinfo



We Like Making Kids Happy ...

Send For Free Catalog

equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094
E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #36 or visit www.eparent.com/adinfo

STATEMENT OF OWNERSHIP

MANAGEMENT AND CIRCULATION

Published annually as required by the U.S. Postal Service

EXCEPTIONAL PARENT. Date: October 2002. Frequency of issue: 12 times per year, January through December. Number of issues published per year: 11 plus special January issue. Annual subscription price: $39.95. Editorial and publishing offices: 65 East Route 4, River Edge, NJ 07661. President, CEO and Publisher: Joseph M. Valenzano, Jr., 65 East Route 4, River Edge, NJ 07661. Editor-in-Chief: Rick Rader, MD, 65 East Route 4, River Edge, NJ 07661. Consulting Managing Editor: Donald P. Mazzella, 65 East Route 4, River Edge, NJ 07661. Stockholders holding 1% or more of the total amount of stock: Alb[illegible]a, Charles, One Kero Road, Carlstadt, NJ 07072; Bell Family Trust, c/o Stephen Bell, 865 Muskingham, Pacific Palisades, CA 90272; Cardinal Associates, 403 River Oaks Dr, Rutherford, NJ 07070; Carver, Dorothy, Box 588, Barnstable, MA 02630; D'Angelo, Robert, 9 Belrose Court, Long Valley, NJ 07853; DeFina, Doris, 6 Robin Drive, Oak Ridge, NJ 07438; Estelle Turner Trust, c/o Howard Turner, 19195 Mystic Palms Drive, Apt. 106, Aventura, FL 33180; Glickstem, Theresa, 1669 Thaddeus Stevens Road, Barnet, VT 05821; Hopkins, Robert K., Jr., 1556 Elgin Court, Keswick, VA 22947; Ianuzzi, Ralph, 3 Spruce Hollow, Upper Saddle River, NJ 07458; Ianuzzi, Steve, P. O. Box 4, Yorktown Heights, NY 10598; Koff, Bernard E., 70 Mayhew Drive, South Orange, NJ 07052; Kupersmith, Corey, 15 Valley Drive, Suite 300, Greenwich, CT 06831; Landers, Allen, MD, 1385 York Avenue - 26F, New York, NY 10021; McCabe, Ed, 151 Merrimac Street, P. O. Box 9147, Boston, MA 02114-9147; McKenna, John, 479 Catmount Road, Fairfield, CT 06430; Parmet, Judith, 12 The Glen, Harbour Acres, Port Washington, NY 10050; Patten, John L., Benchmark Capital, 5 Saddle Hill, Far Hills, NJ 07931; Rossano, Kenneth R., c/o Cassidy and Associates, 75 State Street, Suite 2200, Boston, MA 02109; Sigma-Tau Pharmaceuticals, Inc.,[1] 800 South Frederick Ave., Ste. 300, Gaithersburg, MD 20877; Spivey, Jane Carlisle, 32E Putnam Green, Greenwich, CT 06830; Valenzano, Joseph M., Jr., 65 East Route 4, River Edge, NJ 07661; Whitaker, Herbert, 13201 Canyon Edge Trail, NE, Albuquerque, NM 8711. There are no known bondholders owning or holding 1% or more of total amount of bonds, mortgages or other securities.

EXTENT AND NATURE OF CIRCULATION

Avg. ea. Issue preceding 12 months		Actual single issue nearest filing date - Oct
44,375	Total # of Copies Printed	35,000
35,174	Paid Circ: Mail Subs	27,009
35,569	Total Paid Circulation	27,404
1,911	Free Distribution	1,705
37,480	Total Distribution	29,109
6,895	Office Use, Leftovers	5,891
44,375	**TOTAL**	**35,000**

I certify that the statements made by me above are correct and complete.
Joseph M. Valenzano, Jr., President, CEO & Publisher

---

[1] Sigma Tau Pharmaceuticals has no influence on any operations of Exceptional Parent (EP) Magazine, including editorial material appearing in the magazine. Per the agreement between Sigma Tau and EP, this is an investment only.

GENDER DIFFERENCES IN ADHD

A nationwide survey released last month found that girls with ADHD face significantly greater challenges than boys with the disorder in the areas of social development and self-esteem. The survey was conducted by Harris Interactive on behalf of Novartis Pharmaceuticals; it looked at perceptions of gender differences in youth with ADHD among adolescents with the disorder (ages 12 to 17 years), parents of teenagers with the disorder, teachers and the general public.

Before being treated for ADHD, more girls than boys reported having trouble making friends, getting along with their parents and finishing schoolwork. Girls were also more likely to report difficulty in being happy and feeling good about themselves.

According to one estimate, nearly 75 percent of girls with ADHD may go undiagnosed, possibly because girls with the disorder show less hyperactivity and aggression than boys who have it. Girls are more likely to have subtler symptoms overall. These may include forgetfulness, anxiety, timidity and difficulty listening. Results also suggest that girls with ADHD are nearly three times more likely to be treated for depression than boys with the disorder: only five percent of boys taking medication for ADHD were on medication for depression before their ADHD diagnosis, compared to 14 percent of girls.

The parents of girls with ADHD are reportedly more willing to seek a medical opinion when it seems that their daughter might have the disorder—92 percent of girls' parents were "very willing," compared to only 73 percent of parents of boys. Also, parents of girls were half as likely to feel outside pressure when deciding whether or not to medicate their child.

For more information on the survey, visit: http://www.hirehealth.com/ci/servlet/com.ci.service.NewsResearch?VIEW DETAIL=1&NEWS ID=46060

NEW CENSUS FINDINGS ON DISABILITIES

Figures from the 2000 US Census show that one of every dozen children and teenagers in the U.S.—5.2 million people between the ages of five and 20 years—has a physical or mental disability. The census counted a total of 50 million people with disabilities in the US population. The decennial count covered a range of conditions, from mild asthma to severe mental illness or retardation; specialists say, however, that it probably understates the number of children with disabilities because the questionnaire did not include such conditions as minor speech impediments.

While these are the first census data collected on children with disabilities in more than a century, figures from other sources indicate that the number of children with disabilities is on a sharp incline. Special-education enrollment has risen at twice the rate of overall school enrollment in the last decade, and increasing numbers of children are receiving Social Security payments because of disabilities.

The reasons for this increase are uncertain, but several possibilities exist. One explanation is that the rise is due to the recent period of dramatic change in our approach to disabilities as a nation. The last ten years have seen the institution of the Americans with Disabilities Act (ADA) as well as the revision and continuing implementation of the Individuals with Disabilities Education Act (IDEA). These laws as well as others have helped to further a relatively new vision of inclusiveness, which is resulting in, among other things, more willingness to report disabilities.

Another factor may be the recent changes in medical care. For instance, low-birthweight and premature babies now have a higher chance of survival, but are still at greater risk of developing certain health problems or developmental disorders. Also, the rise of childhood obesity is leading to other conditions such as diabetes. These things and more lead to a growing population of children with disabilities.

Wider recognition and changing definitions may also affect the numbers. Conditions such as attention deficit disorder (ADD), which decades ago was not even recognized, let alone diagnosed, are now included in the disability category. Diagnosis of these conditions has become aggressive, and many more people may be stepping forward because of lessened stigma or the availability of benefits.

Whatever the reasons, the increase results in several challenges. National enrollment in special education services is actually higher than the census total. In addition, educators say that more children seem to have multiple disabilities, requiring more intensive services and incurring additional costs.

Since modern medicine is increasing the life expectancies of people with conditions such as cystic fibrosis, Down syndrome and spinal cord injuries, there is a growing need for services later in life as well. For instance, people with multiple disabilities who may not be able to work or care for themselves after graduation will need adult day care or residential placement. Situations such as this need greater consideration now.

These challenges are amplified in poorer areas. Surveys have shown that poverty can be linked to a higher rate of disability, although the reasons for that are still being debated. Experts offer several explanations, such as insufficient or non-existent prenatal care, a higher risk of premature birth, birth to a drug- or alcohol-addicted mother and the likelihood of increased exposure to lead paint, which can cause brain damage.

For more information on the 2000 Census, visit: http://www.census.gov/main/www/ cen2000. html

We now have a new monthly in depth look at reports and studies on issues that affect the special needs community. Each issue will feature information on the latest medical and scientific updates that apply to our readers.

WWW.EPLIBRARY.COM

EP LIBRARY

Exceptional Parent

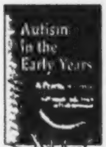
THE SPECIAL NEEDS BOOKSTORE

AUTISM

Thinking In Pictures
My Life With Autism
Temple Grandin with a Foreword by Oliver Sacks

The author is a gifted animal scientist who has designed one third of all the livestock handling facilities in the US. She is also autistic, a woman who thinks, feels, and experiences the world in ways that are incomprehensible to the rest of us. In this unprecedented book, the author delivers a report form the country of autism. Writing from the dual perspectives of a scientist and an autistic person, we learn how the country is experienced by its inhabitants and how she managed to breach its boundaries to function in the outside world. What emerges is a document that sheds light on the riddle of our common identity.

RH118AT **$17.00**

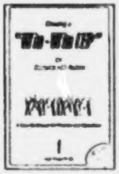


NEW

Autism In the Early Years
Resource Materials for Teachers: A Practical Guide
Val Cumine, Julia Leach and Gill Stevenson

Designed to provide parents and professionals with an insight into the nature and educational implications of autism, particularly as it presents in very young children. Also aims to equip Early Years practitioners and parents with knowledge of a range of intervention strategies to promote learning, social development, communication and appropriate behavior.

TT5992AT **$25.95**



NEW

Creating a "Win-Win IEP" for Students with Autism
A How-To Manual for Parents and Educators
Beth Fouse, Ph.D.

This Second Edition, has been written to provide parents and families of students with autism necessary information and skills to meet the challenges of the IEP process. This book takes readers through the child-centered educational process from the stages of initial diagnosis to implementation ad of student's individualized educational programs. Practical suggestions are provided based on federal and state legislative requirements, case law, and the many years of experience the author has in working with the process as a teacher, special education administrator, regional special education consultant and university instructor.

FH7287SE **$29.95**

NEW

A User Guide to the GF/CF Diet for Autism, Asperger Syndrome and AD/HD
Luke Jackson; with appendices by Jacqui Jackson; Foreword by Marilyn Le Breton

Luke Jackson, who is 12 years old and has Asperger Syndrome, tells you everything you need to know, both good and bad. He offers encouragement and practical advice on what to expect when beginning the gluten and casein free diet, how to alleviate any initial discomfort, and how to live with the diet.

TF0551AS **Cost: $17.95**

Gift Certificates now available for the holidays!

Start the holidays with the "Gift of Knowledge"
Think of your teacher, doctor or friends!
Call 800-535-1910

NEW

Special People Special Ways
Arlene Maguire; Illustrated by Sheila Bailey

This book presents a positive image of persons with disabilities using a delightful rhyme and rich watercolor illustrations. It shares the message that even though each of us may have something different about us, we share many commonalties.

FH7651CH **$14.95**

If The World Were Blind
A Book About Judgement And Prejudice
Karen Gedig Burnett with illustrations by Laurie Barrows

This fascinatingly unique children's story is relevant to everyone, not just the children it is written for. You will find yourself asking how you view people, and what if, you couldn't view them at all?

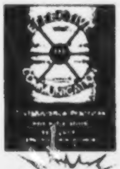
GRP3040VI **$17.95**

Always Kiss Me Goodnight
Instructions on raising the perfect parent
Compiled by J. S. Salt

Instructions on raising the perfect parent as seen in the eyes of 147 children. One of the most popular, entertaining, and insightful books a parent will ever find.

RN10900 **$7.00**

EDUCATION

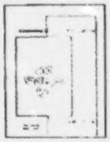


NEW

Effective Communication
Collaborative Practices For Educators
Strategies for Effective Communication
Patty Lee, Ed.D.

This new revised edition includes 60 strategies and 180 practice activities designed to improve communication and collaboration skills. The activities may be used in any order allowing you and your colleagues to focus on one specific area or work in several areas simultaneously! Covers six (6) critical areas: Developing Expectations; Preparing Ahead; Understanding Perspectives; Listening; Asking Questions and Speaking Clearly.

PP5267ED **$19.95**

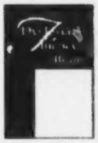


Cooperative Learning and Strategies for Inclusion
Celebrating Diversity In the Classroom
Jo Anne W. Putnam

This guide shows educators how to make group learning strategies work in their classrooms. There are chapters written by a distinguished array of professionals who reveal the real educational benefit of a cooperative learning environment.

PB167ED **$26.95**

DYSLEXIA



Dyslexia, Fluency, and the Brain
Maryanne Wolf

Consider the time it takes for the brain to process written language. What impact does the brain's processing time have on reading, development? What are the relationships among processing time, reading fluency, and dyslexia? Can time and fluency related problems be changed? How should intervention be designed to address the issue. This monumental resource presents evidence indicating that many dyslexic children have a second core deficit in rate of processing linguistic differences in multiple areas. This book has been constructed to bring several levels of evidence and types of research to bear on these questions.

YP26020Y **$30.00**

NEW

Learning About Learning Disabilities
Second Edition
Bernice Wong

Targeted for the advanced student and professional this text covers a wide range of topics to ensure a comprehensive and balanced coverage of important areas in learning disabilities. Included are conceptual issues, basic research in memory processes and social aspects of learning disabilities intervention research in academic areas and nonacademic areas, issues in service delivery and a life span perspective.

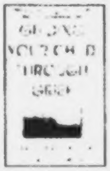
ACP5321LD **$59.95**

GRIEVING

What on Earth Do You Do When Someone Dies
Trevor Romain

A down to earth explanation for children about death. It offers many ways for children to cope with and understand what is happening.

FS4000E **$7.95**



Guiding Your Child Through Grief
Mary Ann Enswiler, MA, MRS, and James P. Enswiler, MA, M.Ed

This caring and compassionate guide offers expert advice during the difficult days to help a child grieve the death of a parent or sibling. This book helps readers understand the many secret ways children grieve and offers more insight information, and advice that can help a child heal.

BD0257GR **$13.95**

Remembering With Love
Messages of Hope for the First Year of Grieving and Beyond
Elizabeth Levang, PhD. and Sherokee Ilse

An affirming gift for those grieving the loss of a loved one, offering compassion, comfort and guidance with over three hundred short pieces written by those who have been there.

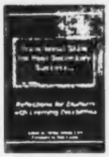
FP0400E **$11.95**

MENTAL RETARDATION

Mental Retardation in the 21st Century
Sponsored by The ARC of the United States, Edited by: Michael L. Wehmeyer and James R. Patton
An interesting and provocative prediction of where technology and society are headed with respect to the treatment of mental retardation in the coming century. Seven Sections covering Family Issues; Education Issues; Employment and Residential Issues; Psychology Issues; Medicine and Health Issues; Life Span Issues and Policy Issues.
PE181MR **$ 44.00**

The Burden of Sympathy
How Families Cope with Mental Illness
David A. Karp
This book captures the essence of caring and caregiving for society today. It carefully discusses the emotional and social forces that are at play when caring for a mentally ill person.
OU3158MR **$25.00**

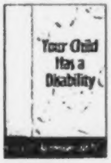
LEARNING DISABILITIES



Transitional Skills for Post Secondary Schools
Reflections for Students with Learning Disabilities
Rick Lavoi and T. Citro
A thorough, extensive resource that will prove to be an invaluable guide for parents and students with learning disabilities. This book not only helps students make the transition from the protective environment of home to the university campus but offers a roadmap, for making that transition, and the college years that follow, a success.
LD7110LD **$24.99**

Einstein and Me: Talking About Learning Disabilities
A Video for Parents, Kids & Teachers
Jerome J. Schultz, Ph.D.
An upbeat, informative and optimistic video of kids talking openly and honestly, telling about how they found out about their learning disability; policies and people who make life difficult; people and programs that helped them cope; their strengths and talents.
LD100LD **$99.00**

GENERAL

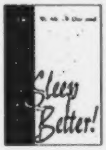


Your Child Has A Disability
Mark L. Batshaw, M.D.
When a child is diagnosed with a disability, parents can be overwhelmed by day to day physical and emotional demands. This comprehensive volume offers some welcome assistance with expert advice on a wide range of medical and educational issues.
PB160LD **$24.95**

The Don't Sweat Guide for Parents
Reduce Stress and Enjoy Your Kids More
Richard Carlson, PhD
This insightful guide provides suggestions for enjoying your children more while being less stressed and more present with them in every moment of their lives. Strategies that are discussed include admitting that you could use some help, learning to take a breather, keeping the job at the office; and many more.
TW7184PA **$10.95**

Is My Child OK?
When Behavior Is A Problem, When It's Not, and When to Seek Help
Henry A. Paul, MD
Every parent has asked this question at one time or another. This wise and compassionate guide offers reassuring words for worried parents as well as concrete ways to spot problems between a normal stage of development… and a true problem. This one step reference book tells parents what is normal, what is not, and where to get help.
RH8879GN **$13.00**

Pathways to Learning in Rett Syndrome
Jackie Lewis and Debbie Wilson
Parents and Teachers of girls with Rett Syndrome will welcome this extraordinary book that offers accessible advice on the special education needs of these girls. It also assists teachers in developing a working knowledge of the syndrome and suggests particular strategies in planning a curriculum which may help overcome the specific difficulties within the diagnosis.
TF5333RS **$26.95**

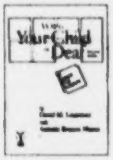


Sleep Better
V. Mark Durand Ph. D.
This text begins with a discussion of sleep followed by a description of a range of sleep problems and includes a step by step interview that will help you identify the type of problems being encountered. Includes treatment options covering bedwetting, sleep walking, insomnia and much more.
PB166GN **$23.95**

HEARING IMPAIRED

The Silent Garden
Raising Your Deaf Child Second Edition
Paul W. Ogden
An up to date reference comprising all the bits and pieces of advice, encouragement and hard data that parents might need in order to make decisions that will enable their children to grow into strong, healthy and productive members of society.
GU103DF **$29.95**

Kid-Friendly Parenting With Deaf and Hard of Hearing Children
A Treasury of Fun Activities Toward Better Behavior
Daria Medwid and Denise Chapman Weston
A step-by-step guide offering hundreds of ideas and methods designed to work with children ages 3 to 12 to enhance communication and strengthen relationships in skillful, fun ways.
GU101DF **$24.95**



When Your Child Is Deaf
A Guide for Parents
David M. Luterman with Antonia Brancia Maxon
This must read book provides information for parents about the emotional and educational processes of coming to grips with a hearing impairment in their child. Parents of newly diagnosed hearing impaired children as well as parents of a child with a hearing impairment at any age will find this book helpful.
YP2270HI **$17.95**

VISUALLY IMPAIRED

Children with Visual Impairments
A Parents' Guide
Edited: M. Cay Holbrook, Ph.D.
Designed to help parents get a handle on common types of concerns. Written by a team of professionals and parents, each of whom is an expert on a different aspect of caring for children with visual impairments.
WB1790D **$16.95**

Transition Issues Related to Students with Visual Disabilities
Jane N. Erin and Karen E. Wolffe
An explanation and analysis of the critical areas in the lives of those with visual impairments, such as transportation, academics, employment and recreation.
PE168VI **$12.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: EP, Dept. EP1002, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call 800•535•1910

QTY.	ITEM#	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

These prices are subject to change without notice.

Name ________________________________
Address ________________________________
City________________________ State ________ Zip __________
Telephone ____________________ E-Mail ____________________

I have enclosed my check payable to Exceptional Parent or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ Exp. Date _____/_____

Signature ________________________________

1211

Circle #200

SUSAN

Susan T. Cheney, 20, graduated this past May from Jefferson Davis High School in Montgomery, AL with a 3.666 GPA, and was selected for inclusion into the 2001-2002 edition of *Who's Who Among American High School Students.* She has also received multiple awards from the Mayor of Montgomery, Bobby N. Bright, who proclaimed May 31, 2002 "Susan Tamara Cheney Day" as well as the Governor of Alabama, in recognition of her courage and achievements despite her disabilities. Susan has Spastic-Athetoid Cerebral Palsey and is non-verbal and non-ambulatory. Her parents, Marilyn and Bob Cheney, aide of 11 years, Kay Smith, and all the rest of her family and friends are very proud of her.

EARL

Earl Delk II, 2 1/2, was born with microcephaly. He is developmentally delayed, but doing well. Currently, Earl receives OT, PT, speech therapy, music therapy and special instruction. He also attends daycare twice a week for socialization. Earl enjoys car rides and crawling through the house. He lives with his parents, Earl and SaBrena, both RNs.

ALYSON

Alyson Lerch, 7, has Lissencephaly. She enjoys lights and sounds, toys, balloons and game shows. Alyson attends Auburn Elementary and likes to spend time with her brother, Cody, and sister, Bree-Anna. She lives in Auburn, Illinois, with her mom, Michelle, dad, Bruce, and her bother and sister.

DALLAS

Dallas Allyn Mahlmann, 4, loves watching TV commercials and being with his family. He wins everyone over with his cute, dimpled chin and huge smile. Dallas receives PT, OT and vision therapy. His parents, Keith and Sherry, are excited about him starting the Early Childhood school program in the fall. He was born premature and has Dandy Walker Syndrome. He uses a wheelchair, a walker, wears contacts and requires oxygen by nasal canula.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (Exceptional Parent), 65 E. Route 4, River Edge, NJ 07661. (Please do not send "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

PART XV

VIGILANCE – INVOLVEMENT – PERSISTENCE

The Keys to Ensure Access to Dental Care

By Sanford J. Fenton, DDS, MDS, FDS, RCSEd, FADPD and Carlton V. Horbelt, DDS, FADPD

The true barometer of a society's ethical and moral values is the way it treats its most vulnerable members: its children, elderly citizens, people who are socio-economically disadvantaged and persons with developmental or other disabilities. Most ethicists therefore judge a society and its members on their deeds or actions rather than their words or rhetoric.

The issue of access to dental healthcare services for all Americans, including those with developmental disabilities (DD), is currently being debated at national, state and local levels. Participants in the debate include government officials and agencies, professional dental organizations, dental schools and dental auxiliary training programs, dental education accrediting bodies or agencies, advocacy organizations, the healthcare insurance industry, parents and/or legal guardians and, most important, individuals with disabilities.

Access to oral healthcare for persons with special needs remains a significant national problem. The decision by many states to close their institutions and relocate individuals to community-based residential facilities has actually added to this access problem. Many of the state institutions that were closed had provided comprehensive dental services through their onsite dental clinics. Closure of these institutions frequently resulted in the dismissal of the onsite dentists and ancillary staff, who often possessed years of invaluable experience. Persons with special needs who were moved to a community setting no longer had access to their professional expertise. The relocated individuals with disabilities and those with the responsibility for finding necessary dental services often discovered a lack of resources and knowledgeable care providers within the community. Continuity of care was frequently jeopardized when individuals with disabilities were relocated to community-based living facilities.

A national advocacy organization, The Voice of the Retarded (www.vor.net), noted that almost two-thirds of community-based residential facilities report that inadequate access to dental care is a significant issue. The Arc (www.thearc.org), a national organization representing people with mental retardation (MR) and related developmental disabilities and their families, reported that people with mental retardation have frequently been denied access to appropriate medical and dental treatment due to their disability. Furthermore, The Arc noted that medical and dental professionals are often reluctant to provide medical and dental treatment because they lack knowledge and understanding of the best practices in treating people with MR, DD and other disabilities.

A national conference called by the Office of the Surgeon General in December 2001 to discuss the issue of health disparities and MR highlighted the plight of many Americans with DD in attempting to access appropriate healthcare services, especially dental care. In the published conference report that followed, Tommy G. Thompson, Secretary of Health and Human Services, eloquently noted that

continued on page 110

continued from page 109

"Americans with mental retardation, and their families, face enormous obstacles in seeking the kind of basic healthcare that many of us take for granted. Unfortunately, societal misunderstanding of mental retardation, even by many healthcare providers, contributes to the terrible burden. Too few providers receive adequate training in treating persons with mental retardation." In this same report, Dr. David Satcher, then-Surgeon General, noted that everyone, including healthcare providers, must recognize the importance of listening to persons with developmental disabilities to learn what needs to be done. Dr. Satcher emphasized that "to listen and not respond with determined action will only heighten the injustice this community has too long endured." Before and during the conference, involved parents and persons with disabilities stressed the following points as major obstacles to accessing necessary healthcare services:

- Lack of provider training;
- Lack of coordination between providers,
- High turnover rate of direct support professionals (DSPs);
- Inadequate level of funding and diverse financial resources for necessary healthcare services.

Additional reports and publications have noted an inadequate number of dental professionals in the community setting willing to treat persons with developmental disabilities. Observations and data from nine years of dental screenings for thousands of athletes during Special Olympics events nationwide have further demonstrated the need to produce more dental professionals who are competent to provide comprehensive services for this seriously neglected population.

Two surveys of American dental schools conducted in the 1990s highlighted the lack of adequate didactic and clinical instruction. The results reported in the 1993 survey indicated that on average, only 12.9 lecture hours were devoted to the dental management of persons with disabilities in a typical four-year curriculum. Equally discouraging, the study found that fully 65 percent of the dental schools offered fewer than 10 hours of clinical instruction in the four-year curriculum. The second study, published in 1999, essentially duplicated the earlier investiga-

Camphill Special School
Children's Village
A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- **Pennsylvania Approved Private School**
- **Waldorf Curriculum (Member of AWSNA)**
- **Both Day & Residential Programs Available**

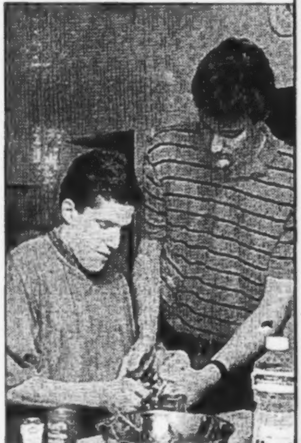
discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236
www.BeaverRun.org

Circle #25 or visit www.eparent.com/adinfo

LIVING & LEARNING

STUDENTS AT THE EVERGREEN CENTER learn to live in the community and reach their full potential. Our Basic Skills and Behavior Development Centers, community residence programs and supportive staff combine to create a caring environment allowing students to achieve a greater degree of personal independence.



Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631
Serving students with developmental, medical and behavioral needs since 1981.

Circle #37 or visit www.eparent.com/adinfo

tion and found that in 53 percent of the schools, the number of lecture hours devoted to special care dentistry had dropped to fewer than five. These two studies clearly showed that dental students do not gain the expertise necessary to treat people with disabilities during their primary dental-education experience. In light of this, it is especially interesting to note that the Commission on Dental Accreditation (the agency responsible for accrediting all dental education programs in the US) eliminated from its Accreditation Standards for Dental Education Programs in 1996 document language that challenged dental schools to provide adequate student clinical exposure to persons with disabilities.

An inadequate level of reimbursement to dental practitioners further complicates the lack of access to necessary services by persons with disabilities. Providing dental services for this specialized population often requires more time and personnel, but third-party payers, especially Medicaid, usually do not reimburse providers adequately. The American Dental Association (ADA), Special Olympics, American Academy of Pediatric Dentistry (AAPD) and Academy of Dentistry for Persons with Disabilities (ADPD) have been working closely with government officials in an attempt to correct this problem. These professional organizations have also established partnerships with other advocacy organizations to address the insufficient number of dental healthcare providers in the field and the deficiency of adequate clinical training for future dental practitioners.

How has the inadequacy in primary training and reimbursement had an impact on individuals in this special population? This case study is just one example.

A twenty-year-old man with MR living with his parents presented with multiple restorable and non-restorable permanent teeth in obvious need of care. This individual was unable to access comprehensive dental services in his local community despite many attempts to find a willing dentist, although his multiple flare-ups of pain and oral infection over a six-month period were treated with antibiotics on several occasions. The parents were finally able to schedule an examination appointment for their son with a dentist who had advanced hospital dental training; he recommended a comprehensive treatment plan involving a same-day hospital general anesthesia procedure to complete all necessary treatment in one session. Unfortunately, acquiring all the information needed prior to the same-day hospital admission proved to be a nightmare. The patient's primary care physician was unable to provide an adequate medical history, although he cleared the patient for general anesthesia on the consultation request form he returned. The assigned anesthesiologist refused to accept this minimal health history and has continued to postpone the scheduling of this patient for general anesthesia. Financial responsibility for these medical and dental services rests with a third-party managed care organization whose pre-authorization policies and procedures for comprehensive dental services in the hospital setting are cumbersome and time-consuming for all the healthcare professionals involved. Inconsistencies in required documentation among the various healthcare professionals and the responsible financial agency have led to an inability to provide the necessary comprehensive dental services in a timely manner. The resultant fragmentation of responsibility for this patient's care has been detrimental to his well-being and quality of life.

Providing dental services for this specialized population often requires more time and personnel, but third-party payers, especially Medicaid, usually do not reimburse providers adequately.

Although it may not be easy to locate a dental practitioner who will provide comprehensive services for persons with DD, parents of children and adults with special needs can succeed in this most important endeavor by becoming a VIP: **vigilant, involved** and **persistent.**

How can a parent or DSP ensure that access to appropriate and necessary dental services will be available when needed for their child or adult dependent with a developmental disability? The first step is to educate yourself about the problem and the possible solutions by being **vigilant.** The Surgeon General's Report on Health Disparities and Mental Retardation is a good place to begin. Another federal agency with excellent information is the National Oral Health Information Clearinghouse (NOHIC), a resource for special care patients.

The second step is to become actively **involved** in your child's or adult dependent's dental care. Ask your dentist to demonstrate appropriate preventive techniques for cleaning their teeth

continued on page 112

continued from page 111

at home. For example, it may be necessary to modify brushing and flossing techniques or positions to accommodate the person's disability. Realize that individuals with special needs deserve the best that the profession of dentistry can provide. Extraction of teeth should only be considered for those teeth that are non-restorable (hopelessly decayed or fractured) or severely involved with periodontal (gum) disease. Restoration of remaining teeth and elimination or control of periodontal disease should be the overall goal.

The third step is **persistence.** If you are unable to access dental services for your child or adult dependent, contact the local or state dental society to solicit the names of dental practitioners in your community who provide comprehensive dental services for persons with disabilities. However, you may need to be willing to travel a reasonable distance to have your child or adult dependent examined and treated by a dentist who is competent to provide dental services for persons with special needs.

If you live within a reasonable distance from a dental school, contact the patient screening coordinator to see if your child or adult dependent can receive care at their facility. If you live near a university that has a University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) on campus, contact the UCEDD for the name of dental practitioners who treat patients with disabilities in their dental offices. Contact the Association of University Centers on Disabilities (AUCD), which provides a directory of all of the UCEDDs. If you have exhausted all available resources and still cannot find a dentist willing to treat your child or adult dependent, contact the director of your state's Developmental Disabilities Planning Council and director of your state's Protection & Advocacy Agency for advice and direction.

The case study below demonstrates what can happen if everyone works together for the welfare of a person with a developmental disability. It is up to government officials and agencies at all levels, professional dental organizations, dental schools and dental auxiliary training programs, dental education accrediting bodies or agencies, advocacy organizations, the healthcare insurance industry, parents and/or legal guardians and, most important, those individuals with disabilities to ensure that this scenario is multiplied countless times in the future.

A thirty-two-year-old patient with severe mental retardation and cerebral palsy living at a state residential facility presented with a need to replace a missing upper front tooth lost due to previous trauma. It was decided that the best treatment approach for this individual would be a dental implant and crown. Under the supervision of the state facility's dental director, all necessary healthcare professionals involved in the planned treatment were notified, documentation—including a comprehensive health history and informed consent—was completed, and financial arrangements were coordinated in a timely manner. This led to a smooth and successful same-day general anesthesia procedure being performed within one month of the initial dental evaluation. This patient currently enjoys a functional and esthetic state-of-the-art dental restoration.

Resources

Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation. Report of the U.S. Surgeon General's Conference on Health Disparities and Mental Retardation, February 2002. (www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf)

Fenton, SJ. People with disabilities need more than lip service. Special Care in Dentistry, 19(5): 198-199, 1999.

Commission on Dental Accreditation. Accreditation Standards for Dental Education Programs. Chicago, 1998.

NOHIC has many excellent publications on a variety of topics related to the dental management of persons with special needs (www.nohic.nidcr.nih.gov).

Directory of UCEDDs can be found at www.aucd.org/directory/directory.cfm.

For information on state programs, visit www.acf.dhhs.gov/programs/add/state.htm.

Universal access to necessary and appropriate dental care is an achievable goal if vigilant, involved and persistent individuals place it on society's ethical agenda for action. EP

Sanford J. Fenton, DDS, MDS, FDS, RCSED, FADPD, is Professor and Chair of the Department of Pediatric Dentistry & Community Oral Health at the University of Tennessee College of Dentistry. Dr. Fenton is also the UTHSC Chief of Dental Services at Arlington Developmental Center and a past president of the Academy of Dentistry for Persons with Disabilities. He also served as Chairman of the Health Promotions: Providers Work Group during the Surgeon General's Conference on Health Disparities and Mental Retardation.

Carlton V. Horbelt, DDS, FADPD, is an Associate Professor in the Division of Community Oral Health at the University of Tennessee College of Dentistry and Dental Director at Arlington Developmental Center. Dr. Horbelt is the current president of the Academy of Dentistry for Persons with Disabilities and past president of the Southern Association of Institutional Dentists.

PRODUCT SHOWCASE

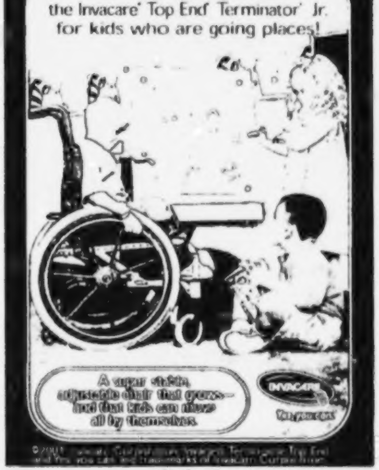
Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

AbleApparel
Bibs, Clothing Protectors,
Rain & Winter Ponchos
• Youth S to Adult XL
• Fashionable Colors and Fabrics
• Waterproof & Breathable

Call for free brochure:
1-888-688-ABLE
Shop online:
www.ableapparel.com

Circle #1

INTRODUCING
the Invacare® Top End® Terminator® Jr.
for kids who are going places!


A super stable, adjustable chair that grows—and that kids can move all by themselves.
INVACARE
Yes, you can.

[illegible]

Circle #2

freedom
what is your
definition?
call us today!

FREEDOM Concepts Inc.

1.800.661.9915
www.freedomconcepts.com

Circle #3

Ability Camp Inc.
Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

Send us your child's photo!

EP is always looking for submissions for our monthly *Familiar Faces* column.

It may just end up on our cover!

Send to: EP, 65 East Route 4, River Edge, NJ 07661

Adaptivemall.com™

Shop On-line!

Tim's daughter Carrie.. a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.
Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston
Copyright 2001 Bergeron Health Care

Circle #23 or visit www.eparent.com/adinfo

MARKETPLACE

ACCESSIBLE TRAVEL

AFFORDABLE WHEELCHAIR VAN RENTALS

Orlando-Miami-Fort Lauderdale by Medical Travel Inc. Disney World Accessible Roll in Shower Villa's for RENT. Thinking of buying a Van—Price us Last. www.medicaltravel.org 1-800-778-7953

BEACH WHEELCHAIR

The Features Make All the Difference !

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure

BEACH SWIMMING POOL

TIRALO™
FLOATING BEACH CHAIR

Toll-free: (877) 244-2810

www.oasisllc.com

TOYS AND HOBBIES

TFH (USA) LTD
4537 6B Sonia RD.
Gibsonia, PA 15044
(800) 467-6222
www.tfhusa.com
e-mail: info@tfhusa.com
Fun products for recreation and education of special needs children. Request a FREE catalog.

CLOTHING

David's Collection

Fashionable & durable vinyl backed terry cloth **BIBS** made to order

Choice of pattern & style

Sm.	$13.00
Md.	$15.00
Lg.	$17.00
plus s&h	$ 3.50

*****NEW*****
Vinyl Backed
Tie Bandanas
$6.50 plus s&h

CALL DAVID'S MOM
for more info — ordering
410-668-0068

Visit: www.DavidsCollection.com

INCONTINENCE

ARC Home Health Products
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider.
Resource information:
www.medmarket.com
e-mail: info@archhp.com

Ask about our Youth/Small Brief sample pack. Only $9.95

HDIS

FREE CATALOG

Call Today!
1-800-2MY-HOME®
(1-800-269-4663)

FREE INFORMATION RESOURCE

TURTLE BOOKS

Jason & Nordic
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends. Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg, PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

EQUIPMENT DEALERS

American
Discount Medical

Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands--Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

EDUCATIONAL MATERIALS

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

Special-Needs W Collection

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

To advertise in
marketplace contact:
Barbara Nastro
Tel: (908) 534-6366
Fax: (908) 534-6941

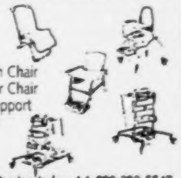
MONITORING SYSTEM

Care Electronics Inc.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price. Call for FREE CATALOG

SEATING & POSITIONING

Designed With Children In Mind
Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Leckey products feature lighter mobile bases, more adjustable components, peer level positioning, child friendly positioning straps and playful colors.

- Freestander
- Totstander
- Easy Seat
- Advance Bath Chair
- Toilet/Shower Chair
- Basic Bath Support
- Pronestander



Call Sammons Preston today at 1-800-323-5547 for a complete Leckey® brochure.

SENSORY INTEGRATION

Sensory Integration Equipment

Providing custom-made weighted items. Sturdy, affordable, comfortable, non-clinical appearance.

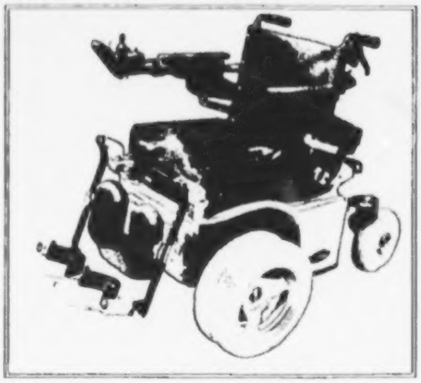
Weight Vests
Weight Blankets

Angel Moon Creations
503-589-9552
www.angel-moon-creations.com
An OT Owned Company

VAN CONVERSION DEALERS

MASSACHUSETTS

Motion Automotive Specialty
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—Day, Week or Month.



OMEGA TRAC

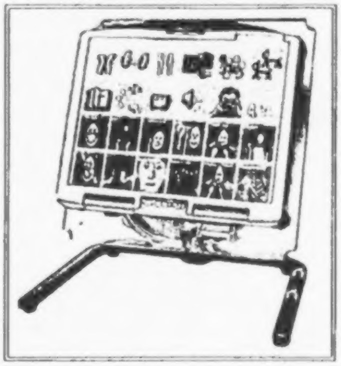
The Omega Trac is an all-terrain, front-wheel-drive, powered wheelchair. It features a transmission steering base and an adjustable powered first class sixty-degree tilt seat. The Omega Trac grows with the child. It is equipped with a single-switch, multi-channel accessory control system, first class locking flip-up arm rests, and first class power elevating leg rests. It comes with removable, add-on dual wheels and a mass-transit tie-down kit. The Omega Trac also features automatic parking brakes that electronically release when movement is initiated and spring-applied while at a stand still.

Teftec Mobility, 12450 Network Blvd., San Antonio, TX 78249. 888-234-1433, 210-477-0330, 210-477-0329 (fax) Email: teftec@teftec.com Web site: http://www.teftec.com

DELUXE POWER PITCH 'N HIT

Gross motor skill development takes on the fun of baseball with the Deluxe Power Pitch 'N Hit, a force-adjustable pitching system. This battery-powered pitching unit comes with an expandable ball holder and features a speed control dial to adjust the pitching intensity, as well as twelve balls and a remote control Rawlings bat that activates each pitch.

funtastic LEARNING, 206 Woodland Road, Hampton, NH 03842
800-722-7375, 603-926-0071, 603-926-5905 (fax). E-mail: sales@funtasticlearning.com
Web site: http://www.funtasticlearning.com



TUFFTALKER PLUS

The TuffTalker Plus is a durable, augmentative communication device designed to assist individuals with upper extremity and communication disabilities. Intended for those who do not use a keyboard, and who prefer touch screen or switch access, this unit features a moisture resistant touch screen, and a height and angle-adjustable mount with rubber grip feet for smooth surfaces. The TuffTalker Plus has an Intel Pentium(r) processor and comes with Windows 98 Talking Screen, E Z Keys, voice synthesis software, Email and internet software. This direct selection communicator is powered by a lithium ion battery or the included AC adapter.

Words+, Inc., 1220 W. Avenue J, Lancaster, CA 93534-2902. 800-869-8521, 661-723-6523, 661-723-2114 (fax). Email: info@words-plus.com Web site: http://www.words-plus.com

TIME PAD

Time Pad functions as a reminder or task prompt, playing up to five messages activated by a timer, or it can be used as a voice output communication aid when one of the five messages is activated by the press of the corresponding button. This device provides a total of seventy-two seconds of recording time divided between the five messages, a digital clock and an alarm that automatically plays the designated message at the preset time.

Attainment Company, Inc, PO Box 930160, Verona, WI 53593-0160, 800-327-4296, 608-845-7880, Email: info@attainmentcompany.com. Web site: http://www.attainmentcompany.com

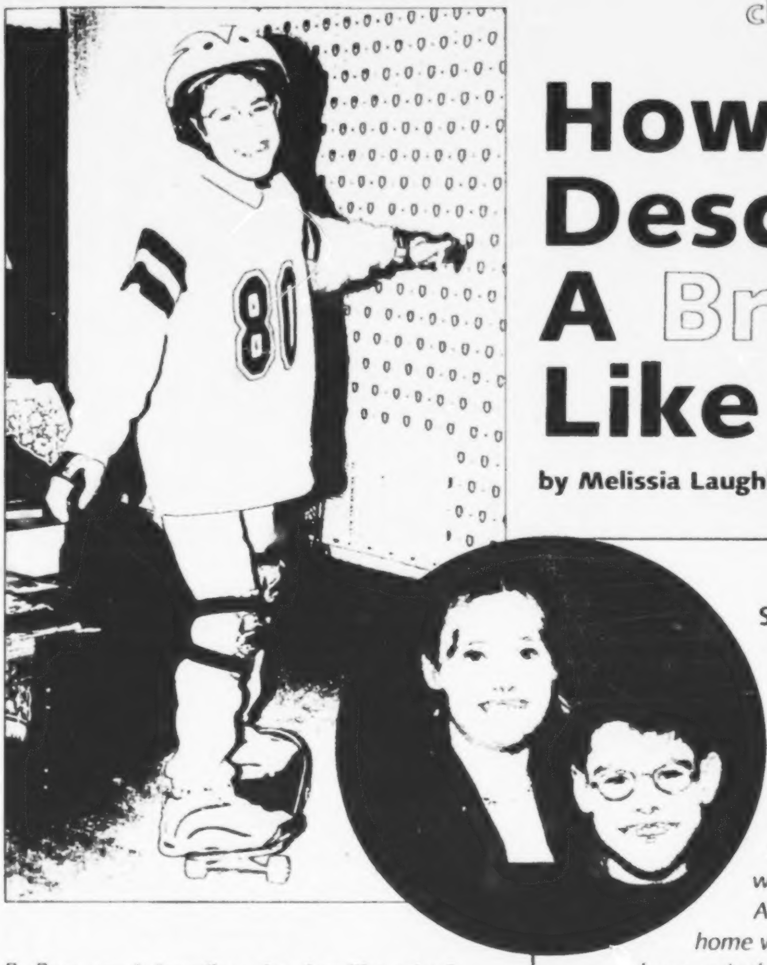
---

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

How Can I Describe A Brother Like Mine?

by Melissia Laughlin



MOM'S TURN

Sandra Birdsong, mother of Melissia and Daniel, writes:

Melissia, 14, is a very passionate and loving sister who cares deeply for her half-brother Daniel, 12. Like most teenage siblings, they bicker and aggravate each other to the fullest of their abilities. But Daniel misses her when she is gone and she becomes bored when he is busy or just behaving himself.

At the moment, Daniel and Melissia share their home with two dogs, Drake and Chigger, who also become jealous of each other!

Daniel receives speech therapy at home twice a week. At school, he receives more speech therapy, PT and OT. We are currently on a waiting list at the University of Arkansas for an evaluation for an augmentative communication device..

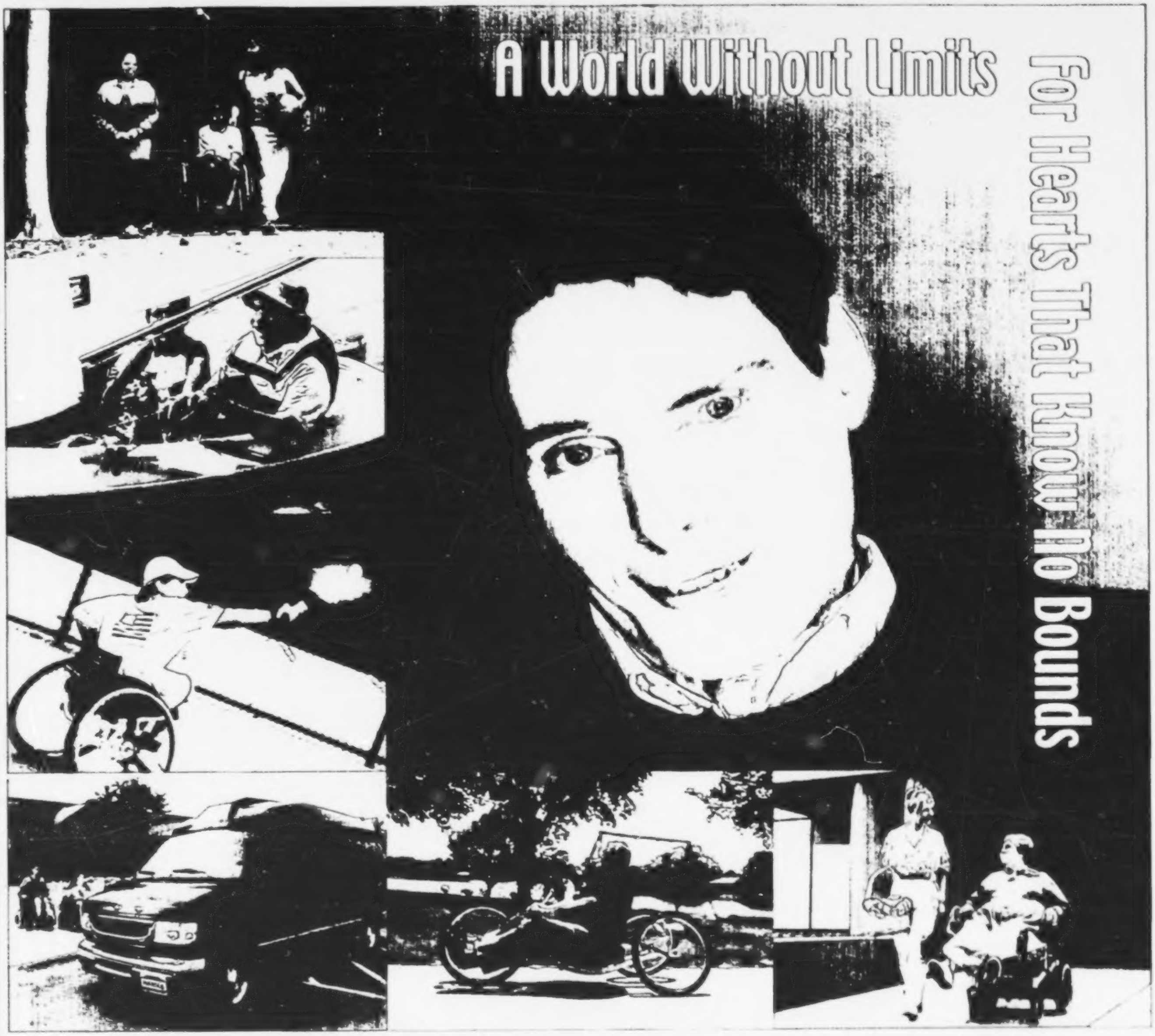
How can I describe a brother like mine? Sure, Daniel may not be completely normal; he may not be able to do stuff like most 12-year-olds do, but I wouldn't want him any other way! He has taught me to be true to myself, to have patience and, above all, to be thankful that I can do so much.

Daniel does not have to put on a mask in order to be recognized, like most teenagers do. He is true to himself and that brings out the sweet and loving boy that he is. No matter what is going on, he always has a smile on his face and a hug to give. Everywhere we go, we seem to run into someone who knows him; I'm not that popular! At times he has his moments of hitting and throwing fits, but these tantrums are his way of testing my patience. Anyone who has a sibling knows that fighting is normal! Each time he has a fit, it seems like I can cope with it better; I know this is true for my parents too. Sometimes I forget that my brother is different than other little brothers, and I wish he were normal. But then I stop and thank God that he has blessed me with someone like Daniel.

Of all the people I know, I think that the one I look up to the most is my brother. He goes through so much. People stare at him and let him down one way or another. Yet he still has strength in him to just smile and love life. So innocent. So pure. That is why I love him so much.

Daniel is like a small ray of sunshine in a dark world. If everyone would just stop and look, they would see what an amazing person he is. EP

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number and e-mail address! ***Now on the Web!*** We now include **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.


A World Without Limits
For Hearts That Know no Bounds

For more than ten years Ford Mobility Motoring has been Ford Motor Company's better idea of a comprehensive process of financial assistance, adaptive equipment information and credit assistance for Ford customers with disabilities and their families.

- Ford, Mercury and Lincoln cars, vans and light trucks. **Vehicle solutions** for every adaptive equipment need!
- Ford Credit Financing provides **purchase and lease solutions** accommodating the special vehicle needs of persons with disabilities and their families.
- Up to **$1,000 in financial** assistance for adding adaptive equipment to eligible Ford, Mercury and Lincoln vehicles.[1]
- Adaptive equipment assessment centers and installer **resource listings** tailored to every state.

Begin your Ford Mobility Motoring experience by calling Program Headquarters.

1-800-952-2248 or
TTY 1-800-833-0312

Visit us on the World Wide Web
www.mobilitymotoringprogram.com

Ford Motor Company
MOBILITY MOTORING

Ford Credit

MOBILITY FINANCING

CHRISTOPHER REEVE PARALYSIS FOUNDATION

The Christopher Reeve Paralysis Foundation (CRPF) encourages and supports research to develop effective treatments and a cure for paralysis caused by spinal cord injury and other central nervous system disorders. The foundation evaluates and selects these research programs using councils of internationally renowned neuroscientists and clinicians. The Foundation also allocates a portion of its resources to grants that improve the quality of life for people with disabilities.

---

[1] The 2003 Ford Mobility Motoring Program is in effect from September 1, 2002 through August 31, 2003. The Ford Mobility Motoring Program will reimburse for the exact amount of the adaptation, up to $1,000 on adaptive equipment and up to a maximum amount of $200 for alert hearing devices, lumbar support and running boards, when you take retail delivery of a new 2002, 2003 or 2004 Ford, Mercury or Lincoln vehicle by August 31, 2003. Total reimbursement is not to exceed $1,000.

Circle #38 or visit www.eparent.com/adinfo

MA7503/08-02

A Better Bedtime Story

The Vail Enclosed Bed

Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for your child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt.
Plus, we provide assistance in obtaining insurance approval.

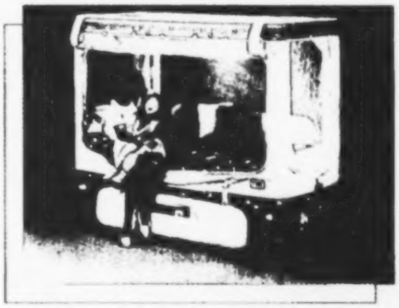
Available from home health-care products dealers, or direct from the manufacturer.

For a FREE catalog, call:
1-800-235-VAIL

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard



Ask about Our Decorator Accessories.

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

Sheri Wittmer
Sandusky, Ohio

Vail Meadows Therapeutic Riding Center

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for challenged riders.

Circle #74 or visit www.eparent.com/adinfo

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent

NOVEMBER
2002 • $4.95

Experts Agree:
Laughter Helps

Comedian Ray Romano Performs for RX Laughter

Managing Stress

Diagnosing Autism

AAMR—
Recognizing and Tracking Pain

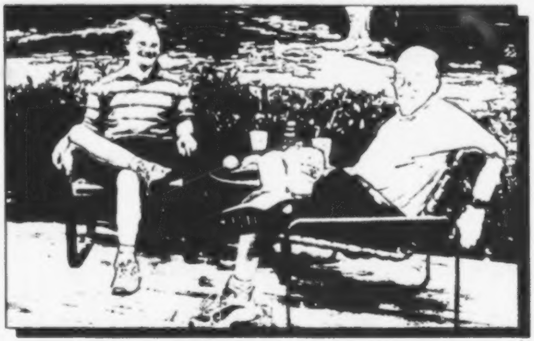
**************************************FIRM 22201
22201AQU111CU00 ZNI02
ACQUISITIONS
ERIC CLEARINGHOUSE
COUNCIL FOR EXCEPT R= 6311
1110 N GLEBE RD STE 300 S116 P2
ARLINGTON VA 22201-4795

BEST COPY AVAILABLE

www.eparent.com

223

The Meadows at Melmark where...



Life begins at 21!

The Meadows Village Community was established in 1975 at The Melmark Home, a beautiful 80-acre campus located on Philadelphia's exclusive Main Line. At the Meadows adults live with their friends in their own supervised homes, perform meaningful work and have a full life of social, recreational and athletic activities. Self-esteem and enthusiasm for life grow as they experience success every day.

The Sound of Music

Celebrating life's achievements

The satisfaction of meaningful work

Challenging leisure activities

MAKOS
MELMARK
MAKOS

The MEADOWS at MELMARK

A Life Community for Adults with Disabilities

2600 Wayland Road, Berwyn, Pennsylvania 19312
For more information call: Peter McGuinness, Director of Admissions
1.888.MELMARK • www.melmark.org

Circle #50 or visit www.eparent.com/adinfo

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

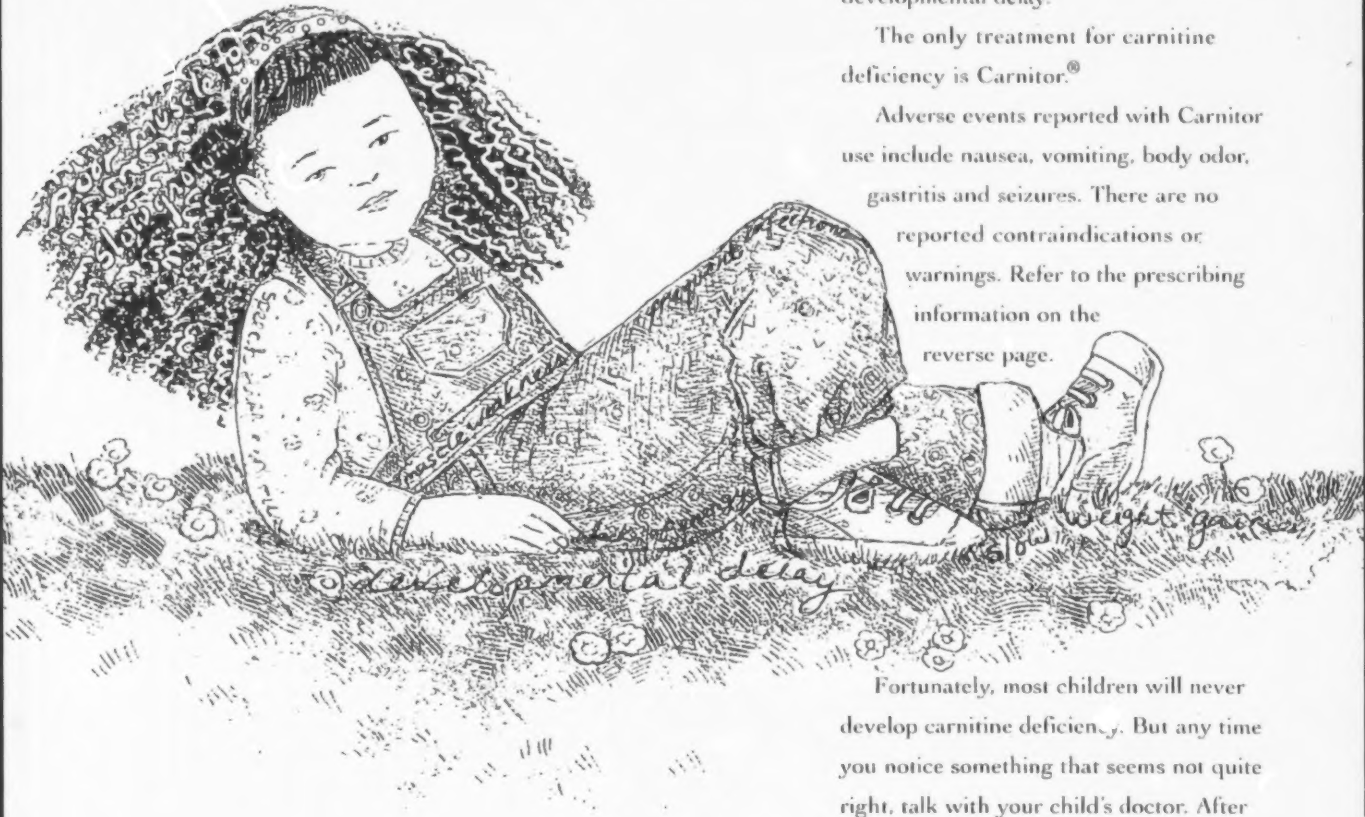
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

contents

NOVEMBER 2002 ◦ VOLUME 32, ISSUE 11

STRESS MANAGEMENT

24 **Rediscovering the Joys of Life**
By Patricia Brown, EdD, Monica Uhl and Jill Baughan
Touching back to smile forward.

28 **RX Laughter**
By Laura Apel
Comedians Ray Romano, Kevin James, Wendy Liebman and others join together in support of the RX Laughter research program.

30 **Journey Through the Land of Oz**
PARENTS TOP TWENTY STRATEGIES FOR MANAGING LIFE
By Kate Scorgie, PhD and Lorraine Wilgosh, PhD
200 parents of children with various disabilities describe in their own words how they navigate the bewildering new world of their child's disability.

39 **Exceptional Parents and the Exceptional Stress of the Holidays**
By Lisa Groen Braner
The author of *The Mother's Book of Well Being* discusses holiday related stress and suggests ways to combat it.

41 **Self Regulation and Stress Management**
By Carolyn Cantu, MS, OTR
An analysis of possible approaches and programs used to reduce disability related stress.

48 **8 Tips for a Stress-Free Holiday**
By Christine Klein
Some helpful tips to maintain a fun and relaxing holiday season.

FEATURES

51 **The Story of a Pediatrician/Parent (two part series)**
By Jo Feingold, MD
The first of a two-part story written by a pediatrician and mother of five who used HBOT for her daughter who has Cerebral Palsy.

63 **Graduation Exit Exams**
By Louise G. L. Nelson and Ann P. Turnbull
Information for parents of people with disabilities regarding state and local school systems mandatory exit exams.

Spotlight on Austism

55 **Continuing Progress in the Diagnosis of Autism**
By Eric London, MD
A look at the challenges and progress in the diagnosis of autism.

60 **Five Early Signs of Autism**
by Connie Kasari, PhD and Connie Worg, MA. UCLA
Researchers have identified five areas of infant behavior indicating the possibility of autism.

69 **Recognizing and Tracking Pain in Children with Developmental Disabilities**
By Sally Colatarci, RN, MS, FAAMR and Wendy M. Nehring, RM, PhD, FAAN, FAAMR
The second of a series of articles by the AAMR (American Association on Mental Retardation.)

72 **Fashion In a Snap**
By Lori Ostrover
Some helpful hints on where to find stylish adaptable clothing and how to make your own clothes more suitable to your individual needs.

90 **WCD Roundup**
A look at the recent World Congress and Exposition on Disabilities held in Orlando, FL.

ON OUR COVER: COMEDIAN RAY RAMANO DURING HIS PERFORMANCE AT THE COMEDY CENTRAL BENEFIT FOR RX LAUGHTER. (See page 28)

EP
Exceptional Parent

contents

DEPARTMENTS

8 **Editor's Desk**

10 **Search & Respond**

20 **What's Happening**

77 **In Depth**
A Randomized, Controlled Trial of a Community-Based Support Program for Families of Children with Chronic Illness: Pediatric Outcomes

79 **Tech Talk**
The Value of DO-IT to Kids Who Did It!
By Sheryl Burgstahler, MD

87 **Org. Spotlight**
International Fibrodysplasia Ossificans Progressiva

92 **Oral Health**
A Vision for the Future
By Clive Friedman, DDS

96 **Familiar Faces**

99 **New Products**

100 **Children's Page**

100

Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy-Ed Corp., dba *Exceptional Parent Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy-Ed Corp. *Exceptional Parent*® is a registered trademark of the Psy-Ed Corp. **Postmaster:** Please send address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *Exceptional Parent*, P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *Exceptional Parent*. Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #4006 0754. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

Exceptional Parent neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
EP advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative nomenclature.

—Rick Rader, MD

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman, Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine, Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics , Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof., Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

HAROLD TURNER, D.D.S., Editor Emeritus, Oral Health

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

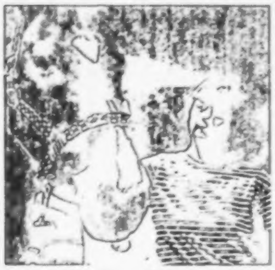
verizon

Circle #60 or visit www.eparent.com/adinfo

A place of *their* own...

A place for encouragement...

A place for friends...



A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Serving Adults having MR/DD

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #17 or visit www.eparent.com/adinfo

EP

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

Editor-in-Chief	Rick Rader, MD
Consulting Managing Editor	Donald P. Mazzella
Assistant Managing Editor	Laura Apel
Medical Editor	Fern Potvin
Assistant Editor	Lori Ostrover
Assistant Editor	Arnold Kim
Assistant Editor	Julia Steele
Book Editor	Megan Henninger
Information Systems Coordinator	Dennis Dusevic
Research Assistant	Susan Jenkins
Graphic Consultant	Dennis Wilkes

President, CEO & Publisher	Joseph M. Valenzano, Jr.
VP Business Development & Internet Projects	Vanessa B. Ira
Contributing Editor & VP Organization Relations	Bridget M. Lyne
Chief Financial Officer	Dolores A. Kinley
Ad Traffic Manager	Kendra Kelly
Sales Coordinator	Doris DeFina
Receptionist/Public Relations Coordinator	Robyn Sager
Art Direction, Design	Publishers Design Group, Inc. ✉annpdg@aol.com
Production Manager	Michael Longobardi
EP Library	Ron Richards (800) 535-1910 ✉eplibrary@aol.com
Webmaster	Ken Fleischer, Dynamic Media Works ✉webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Vanessa B. Ira
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 ext. 209
✉ vira@eparent.com
CANADA

Annabelle & Gabe Jacobson
The Lyon Group
806 Lawler Aveenue
Wilmette, IL 60091
(847) 256-6850
✉ bellyon@meganet.net
MI, WI, IA, IL, IN

Bill Joubert
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ bjoubert@superlink.net
MT, ND, MN, SD, WY, NE, KS, OK, TX

Jared Adams
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉jadams@eparent.com
DE, MD, DC, WV, VA, NC, SC, GA, FL, KY, TN, AL, MS, LA, AR, MO

Matt Valenzano
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 x211
✉mattvalenzano@eparent.com
ME, VT, NH, MA, RI, CT, NY

Brian Regan
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ unregan@sprintmail.com
PHARMACEUTICALS

Larry Battistello
Marketing Plus
3155 East Ramon, Unit #203
Palm Springs, CA 92264
✉ seeme4ads@aol.com
TERRITORY: WA, OR, ID, NV, CA, UT, CO, AZ, NM

Barbara Nastro
65 East Route 4
River Edge, NJ 07661
(908) 534-6366
(908) 534-6941-fax
✉ nastro@blast.net
NJ, PA, SCHOOLS, CAMPS & RESIDENCES, MARKETPLACE

Color Separation/Film Preparation
AGT7 Carlstadt, NJ 07072

List Rentals
GRS
Mktg Services Inc.
187 Billardvale Street
Wilmington, MA 01887
Attention: Mark Hammar
978-661-8126
mhammar@mktgservices.com

Publishing & Editorial Office
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

Subscriber Service:
Exceptional Parent
P.O. Box 2078, Marion, OH 43306-2178.

Customer Service/New Orders:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

Exceptional Parent magazine was founded in 1971 by Maxwell J. Schleifer, PhD

MPA

For subscription and advertising information, see page 82

Get-A-Round Gait Trainer

Freedom Designs, Inc. is proud to introduce the new Get-A-Round Gait Trainer. The Get-A-Round offers a "fresh new look" to the gait trainer market. Two sizes are available: small and medium. The Get-A-Round boasts multi adjustments for different functional needs, along with many frame and fabric color choices. The Get-A-Round promotes versatility and function with style.

FREEDOM DESIGNS
INCORPORATED ®

MULTI-FUNCTIONAL CASTER

NOTE: Caster Fork Swivel Lock
L- Caster Lock
R- Caster Ratchet (One Way Roll)
F- Caster Free Wheel

2241 Madera Rd., Simi Valley, CA 93065 USA • (805) 582-0077 • (800) 331-8551 • Website: www.freedomdesigns.com

Circle #33 or visit www.eparent.com/adinfo

Bad Guessers and Bad Guesses

It's after the diagnosis. Physicians are most uncomfortable with it. They hardly offer it and at times waffle on it. It's not reimbursable and there's no code for it. Clinicians don't receive any training in it. It's usually preceded and succeeded by silence. No drug company has ever sponsored a lunch-time symposium on it.

But it's probably the one piece of information parents, spouses and patients cling to and refer to from that moment on. It has probably moved more people to action than declarations of war, memorable prose and unforgettable lyrics combined. It's the prognosis, and exceptional parents have heard every possible rendition, version and contortion of it.

Parents and patients might fear the diagnosis but it's the prognosis that serves as the mule kick to the head. The poet and novelist Sir Walter Scott remarked about the prognostication skills of physicians, "they are bad guessers." While it's true that specialists in oncology, critical care and traumatology probably have the most experience in prognostication, there are often large discrepancies in projected outcomes in identical cases.

Despite the contributions of biostatistics, medical informatics, disease staging studies and global pathological registries, the answer to the questions "how long," "how much," and "how bad" is guess-based, guess-driven and ultimately, guesstimated. The lingering question of "how come" is often also answered with a guess.

Nicholas A. Christakis, MD, PhD, a physician cross-trained in sociology, has examined the dynamics of physician prognostication. In his book Death Foretold, he notes that "there are three complementary ways in which physicians may understand and in the broadest sense, control a patient's disease: they can identify it, eliminate it, or predict its course. All three—diagnosis, therapy and prognosis—are means by which physicians come to terms, clinically and cognitively, with disease."

Exceptional parents, most notably the parents of children with abbreviated lifespan disorders (like the ones I rub shoulders with daily at Orange Grove), usually discard references to both their children's disease and therapy and relate to the time element. "Rick, I don't know how much longer Chad has, but for as long as he lives he will live with us," or "Rick, Robbie has already lived longer than anyone thought he would, we're now off the chart." "Rick, the pediatricians hardly ever look at me in the halls, not since they told me that Gwen wouldn't survive the night…and that was twelve years ago."

Dr. Albert Lamb wrote in the Journal of Chronic Diseases, "Patients and their families will forgive you for wrong diagnoses, but will rarely forgive you for wrong prognoses." Most parents of children with special health care needs are more interested in hearing that their physicians and health care teams will partner with them, will be there "the whole time," that their interest, energy, and attention won't diminish with any prognosticated shadows.

> *"The only thing I can say for sure about prognosis is that you are bound to be wrong—unless you are so vague that the prediction is meaningless."*
>
> *—An internist interviewed for Death Foretold*

Exceptional parents usually find themselves in the epicenter of prognostication. Their strategies, "Plan Bs" and energy stores pivot around answers to "how much longer," but not solely in the white-coat realm. "How much longer until the next level of insurance kicks in…how much longer till we know if he's inclusion bound…how much longer will we be on the waiting list?" The only thing that becomes predictable is the oh-too-familiar response, "it's hard to tell; we'll know better as time goes by." Try using that line the next time someone asks you, "how much longer till dinner's ready?"

For Exceptional Parents the prognosis is always something you didn't count on. ■

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

ORIGINAL
EDENSOY
RGANIC SOYMILK
EDEN 8.45 FL OZ 250ML
EDEN ORGANIC
GREAT NORTHERN BEANS
EDEN ORGANIC
APPLE JUICE
EDEN ORGANIC
Vegetable Alphabets

EDEN®

Our Children... Our Hearts

Nurture them with Good Food.

n Eden
Production
Supervisor

At Eden this means: **no irradiation, no preservatives, no chemical additives, no food colorings, no refined sugars, no genetically engineered ingredients** ~ the safest, most nutritious, certified organically grown food that can be acquired.

More than 200 EDEN® foods are available at discerning retailers in the U.S.A. and Canada.

Pure Food is Our Passion, Great Taste is Our Joy.

Ⓚ parve

Visit **www.edenfoods.com** for over 500 free recipes and product information.

© 2002 Eden Foods, Inc., Clinton, Michigan 49236 • info@edenfoods.com • 888.424.EDEN

Circ adinfo

Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: EP Magazines, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Accessible Homes

I will be moving to a new house and want to build a wheelchair accessible ramp or deck. I realize that most counties mandate designs and that I will have to follow their requirements. Does anyone know where to go to find these designs or know of a web site or merchant that specializes in this field?

—DB via EP Web Site

S

Feeding Problems

I have two children that were diagnosed with Familal ExudativeVitreoretinopathy (FEVR) and are now both legally blind. My main concern is my son's eating habits. Since last year's emergency surgery to relieve the elevated pressure within one of his eyes, he has become hard to feed. He will only eat certain items and sometimes he will eat only one sandwich all day. He also has a habit of chewing on his bed sheet at night. Does anyone have any suggestions on feeding him?

—P via EP Web Site

I am the parent of a 14-year-old daughter with Down syndrome and longstanding hypothyroidism. My daughter is an extraordinarily picky eater. Extremely strong willed, she refuses to try any new foods, not even a taste. Consequently, her choice of foods is limited to four or five dishes. Does anyone have any suggestions or ideas to get her to try new foods?

—Anonymous via EP Web Site

We are the guardians of our ten-year-old granddaughter who has cerebral palsy, seizure disorder, cortical blindness and does not speak or walk. She currently takes Tegretol and Depekene three times a day to control her seizures, which has been working for about two years, but during this time period her appetite has almost disappeared completely. The one thing that was always a joy for her was her food and now she refuses to eat. We think that the medicine may be the cause but the neurologist disagrees. On days that the medications have been delayed in order to do blood work she seems to eat better. Has any other family had a similar experience with these medications and should we change medications in order for her appetite to return even though the seizures are under control at this time?

—DM via EP Web Site

S

Developing Fine Motor Skills

I am trying to work with my daughter on improving her fine motor skills. Though I want to have her work with small objects such as marbles, she mouths many of her toys. We are working on oral-motor skills to alleviate this problem, but while this therapy is underway I still would like to work on fine motor skills as well. I have been looking for an athletic-like helmet with a face guard for her to wear during fine motor work, but most are cumbersome and block her vision. I redirect her when she tries to put something inappropriate in her mouth, but sometimes she is quite fast and gets the object in before I can stop her. Does anyone have any ideas on a way to block access to her mouth while we work with small objects?

—Anonymous via EP Web Site

S

Aicardi Syndrome

My two-month-old daughter has recently been diagnosed with Aicardi syndrome. I am looking for information or support from other families with daughters who have this condition and I am particularly interested in information for seizure control.

—CM via EP Web Site

continued on page 12

Solutions for Daily Living
from Columbia Medical

Transporting

Since 1986, the **Columbia Orthopedic Positioning Seat** has been parents and therapists first choice in car seats. Suitable for children 20 to 102 lbs., it meets or exceeds all safety standards while offering the maximum in comfort, support and adjustability. Available with swing-away abductor, seat depth extender, buckle-guard and extensor thrust wedge accessories. Includes full-positioning pad set to customize fit and grow with the child.

Weighs only 11 lbs.

MOBILITY BASE

The Columbia Orthopedic Positioning Seat locks easily and securely onto the customized **Mobility Base.** The strong, lightweight frame offers three-angles of tilt and a height-adjustable footrest. Large wheels permit a smooth ride over any surface.

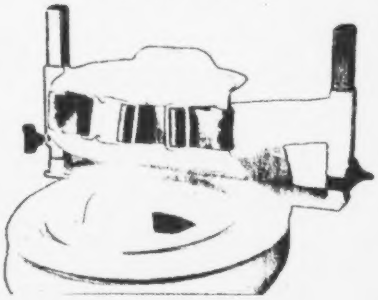
Bathing

Extension legs and casters are available to easily convert bath chair into a rolling shower chair.

Our NEW Fully Customizable Bath Chair, **Contour Ultima™** is completely configurable to meet an individual's unique needs. It offers the ultimate in positioning options and comfort. Available in four standard sizes and 192 custom-made combinations, the chair's seat, back leg length and seat width can be specified. The seat and back sections independently articulate providing full head and trunk support in both the sitting and reclining positions. Made of surgical grade stainless steel and replaceable ComfortMesh™ fabric. Includes two positioning belts for additional safety and security. The chair is sturdy, lightweight, easy to clean and fits in any standard tub.

Toileting

Our **Toilet Supports** attach and remove easily from any toilet. Available in both low and high backs, the supports can be used by children and adults.



Free Standing Bedside Positioning Commodes can be used independently or positioned over any standard toilet.

Columbia 800-454-6612 ext. 100
e-mail info@columbiamedical.com ◦ www.columbiamedical.com

Since 1978, Columbia has manufactured products exclusively for individuals with special needs. All of our products are made in the USA of durable materials, are tested to the highest standards and are designed for maximum safety and comfort.

Circle #23 or visit www.eparent.com/adinfo

Search & Respond

continued from page 10

S

Car Safety

My daughter undoes her seat belt while riding in the car. We had a cover for the seat belt latch, but it has been misplaced. Does anyone know where we can buy another seatbelt latch cover or some other device to keep her safely belted in the car?

—Anonymous via EP Web Site

S

Cerebral Palsy Symptoms

My three-year-old son, who was born at full term after an uneventful pregnancy, was "diagnosed" with CP at 15 months of age. This was a clinical diagnosis, however, as both his head and spine MRIs were normal. Other than a delay in walking, which he didn't accomplish until 19 months, he met all milestones at the "normal" time. But now he has problems with spasticity in his legs and a weak trunk. I am just baffled as to how CP can just "show up" after having been a perfectly developed baby with normal range of motion skills. Is it common for CP symptoms to just appear out of nowhere and not have any damage show on the MRI?

Respond

R

Menstruation with Down Syndrome

DD, the mother of an eight-year-old daughter with Down syndrome, is looking for information on what to expect when her daughter begins menstruation.

My 16-year-old daughter with Down syndrome started her period when she was 11. She has been able to change her pad and likes to keep it clean. Although going to the bathroom is not a priority, she is annoyed when she waits too long. She now wants her menstrual flow to end sooner than it does. She has a friend with Down syndrome who receives a hormone shot to stop her periods from occurring.

—PZ via EP Web Site

I started worrying about my daughter's period shortly after her birth while she was still in the surgical intensive care unit, and prayed she would be at least 16 years old before she started. To approach the issue, I always allowed her to be in the bathroom with me and talked openly about periods. But I continued to worry. She is now 15 years old and started her first period about one year ago and has been successful in accepting and handling the functions of caring for herself. Our biggest dilemma right now is when she has her period over vacation. (She loves to swim.) I am currently looking for a gynecologist who will work with us to deal with that issue. Good luck! Your daughter will probably handle getting her period much easier than you ever thought.

—P via EP Web Site

R

Infantile Spasm Treatments

A has a one-year-old son with lissencephaly and seizures called infantile spasms and would like to hear from others with similar experiences.

We have a son who was in a similar situation. He is eight years old and is diagnosed with Miller-Dieker Syndrome Lissencephaly. Our son also experienced infant spasms when he was a baby, which were treated with ACTH. Unfortunately, two months later, the seizures returned and now our son has tonic clonic seizures. Dealing with his epilepsy is definitely a big issue for us. I have found some wonderful support through the Lissencephaly Network (www.lissencephaly.org). There is also a conference coming up next summer in Long Island, NY where you can find an abundance of information. The conference has physicians who are researching this condition and its effects. Current treatments for seizures are usually discussed. Also, the Network might be able to connect you to someone in your area that has a child with Lissencephaly like ours. I am so grateful to the organization for all the help it's given us in the past eight years and I'm sure it'll be a big benefit for you as well

R

Toilet Training

C has a four-year-old son with Duchenne Muscular Dystrophy and developmental delays who is having difficulty potty training. The doctor said that his condition should not be interfering with his ability to control his bladder or bowels She is looking for suggestions on how to improve his situation.

I am in the process of potty training our six-year-old, which I have continued to do for about two years. Our little girl has CP and the doctor said it would take a long while for her to feel and control her urges. At first I sat her on the potty every 30 minutes. If she happened to go, I rewarded her with a sticker, which she got to put on her poster. As she got better we upped the ante. She still has lots of accidents, but she can last 2 to 2 1/2 hours. I hope this has helped.

—F via EP Web Site

R

Seeking Information on Vacation Ideas

Anonymous was looking for any information on resorts and vacation spots that offer care for children with special needs.

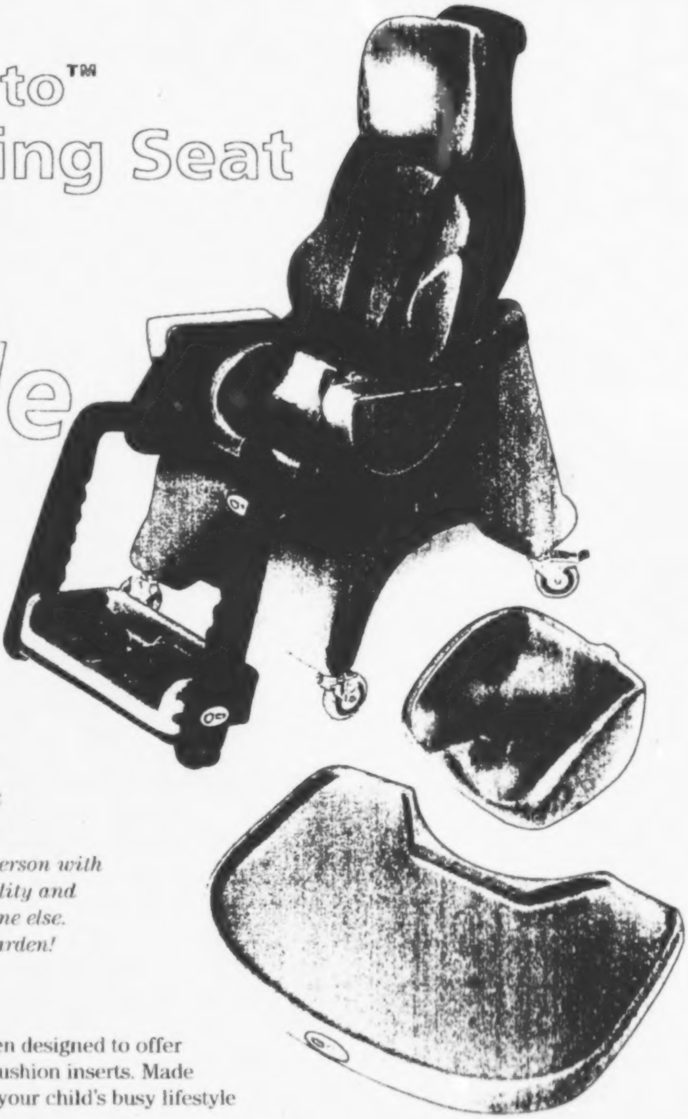
I have a daughter with cerebral palsy. She is nonverbal, has seizures and spasticity of all her limbs and is very sensitive to noise. We took her,

continued on page 14

SPECIAL TOMATO

Special Tomato™ Multi-Positioning Seat

adjustable
adaptable
versatile



My dad and mom had four children. The first three were healthy and regular people. Then I came along; a baby with a difference—Down Syndrome.

One day it was bothering me that I was having a hard time doing my school work. My dad shared a story about his tomato garden. Once, at harvest time, a differently shaped tomato got his attention. It had a large, bright red bump that made my dad want to pick it up and study it because it was so unique and looked appetizing. At dinner, that tomato was just as juicy as the others.

Even though I'm different—like the tomato—as a person with Down Syndrome, my lovable and outgoing personality and strong character make me just as special as everyone else. I guess I am the special "tomato" in our family's garden!

The Special Tomato™ Multi-Positioning Seat (MPS) has been designed to offer comfortable and proper positioning support with its soft cushion inserts. Made for use at home, on the bus, at school, and anywhere else your child's busy lifestyle takes them.

Built to accommodate your child's growth, the unique design of the Special Tomato™ Multi-Positioning Seat allows you to make simple adjustments as needed.

Meets ANSI/RESNA WC/19 safety regulations for bus or van transport

Special Tomato™ Multi-Positioning Seat

The Special Tomato™ Multi-Positioning Seat (MPS) is available in three different configurations. Use the MPS with the Mobile Floor Base for use at home or in school. The MPS can also meet your bus or van transportation needs with the Push-Chair Base. If you prefer, the MPS can be purchased separately and attached securely to most standard chairs in your home, in the classroom, or in the community.

At home or school

SAMMONS PRESTON Rolyan

Special Tomato™ products are brought to you exclusively by Sammons Preston Rolyan

For more information, contact your local Special Tomato dealer or call Sammons Preston Rolyan at 1-800-323-5547

Circle #55 or visit www.eparent.com/adinfo

Sammons Preston Rolyan
An AbilityOne Company
4 Sammons Court
Bolingbrook, Il 60440-5071
Phone: 1-800-323-5547
FAX: 1-800-547-4333

continued from page 12

her three siblings and my parents (8 of us in all) to Disneyland a couple of years ago and she had the time of her life. The staff there was very sensitive to her needs and they were all well prepared to help us with her. We were not required to stand in long lines when it was hard for her and most of the rides had a seat that could be specially adapted to strap her in safely. We took it slow, and it turned out to be a great vacation for all.

—C via EP Web Site

School Yard Harassment

Anonymous has a 14-year-old son with mild to moderate mental retardation, speech difficulty and learning disabilities. He also has problems at school, where he is faced with harassment and bullying from other students. A would like to know how to encourage and build up confidence in him, as well as find out about anything the school can do to ameliorate the situation.

When a similar series of events occurred with my child, I got an Individualized Education Program, or IEP. I recommend that all your son's needs be met through formal written IEPs. Contact your local regional center for a no-cost advocate who will attend the meetings with you, support and help you. Also, ask for a one-on-one aide for the playground. My school had very sociable college students working with some of the special needs kids. They can help in most situations and in my son's case, his aide was so "cool" that the other kids began hanging around both of them at lunch. Even the kids who started as tormentors later became friendly and tolerant when they saw my son wasn't so bad after all. A lot of this teasing is out of fear.

As far as coping skills go, these can be learned with the assistance of the school psychologist (ask for help in this area) and private discussions at home. I always talk about forgiving people because they don't know better. This helps my son a lot and keeps him from holding grudges.

—DSO Via mail

Braces for Children with Down Syndrome

K has an 11-year-old daughter with Down syndrome whom the family dentist recommended get braces and K would like to know whether or not the outcome is worthwhile.

I don't have the answers when it comes to braces, but I can tell you that we are in the same position. Our pediatric dentist referred us to an orthodontist for evaluation of my 15-year-old daughter. Much to my surprise, the orthodontist was very optimistic about braces even though my child has many oral motor issues including tongue sucking, finger chewing, hyperactive gag reflex and others. The orthodontist believes that many of these issues will improve with treatment, which has not begun because of my daughter's baby teeth. He wants to wait for most permanent teeth to erupt, which shortens the amount of time she would wear braces. According to a friend of mine whose daughter has braces, the biggest difficulty is making sure that the teeth are clean behind and in between the fixtures. Good luck.

—PB via EP Web Site

Looking for Schools

Anonymous is looking for a school in which she can place her 15- year-old daughter who has multitple disabilities.

My son is 16 years old and has similar issues. He was born at 27 weeks gestation and suffered a Grade four intraventricular hemorrhage, seizures, spastic diplegia, total blindness and hydrocephalus. He now has scoliosis and PDD with self-injurious and aggressive behavior. His self-inflicted injuries have always been challenging for us and for the school system. After two hospitalizations in our state mental institution (no private hospitals would accept him due to the severity of his behavior and the multiple disabilities), we had an emergency IEP and the school searched the country with us to locate a residential school who would accept him. Many schools did not want to evaluate my son due to his blindness, which made him unable to fend off another student's attacks. The social worker found Heartspring School in Wichita, KS. They have had other students with visual impairments so they agreed to evaluate my son. Our experience with Heartspring has been very good. It is difficult to know your child is having painful issues and you can not be there to comfort them. Heartspring does a fantastic job at learning about the child's interests so they feel morecomfortable.

BM via EP Web Site

COMMENTS NEEDED

If you have experience with the following situations—as a parent, a professional, a direct support professional, a patient—**EP Magazine** would like to hear from you.

Multiple conditions (comorbidity) in which drug therapy was utilized. In particular, we are interested in epilepsy, autism and other neurological disorders, but the survey is not limited to these conditions.

We would particularly like to know about comorbidity of depression, autism and ADD/ADHD.

Please send a brief summary of your experiences to epedit@aol.com. Include your name, email address or phone number. You may write to:

Laura Apel
Assistant Managing Editor
EP Magazine
65 East Route 4
River Edge, NJ 07661

All replies will be kept confidential, but you may be contacted for a series of articles EP Magazine is preparing for 2003.

Convaid

- 10 - 45° adjustable tilt
- 90 - 105° of seat back angle adjustment
- Rodeo 12" weighs only 23 pounds with footplate
- Adjustable seat depth grows with the child
- Height adjustable push handle for parent's comfort
- Optional storage tray under frame
- Folds at any angle of tilt
- Folds with all positioning options in place
- Available in 7 bright colors

Rodeo

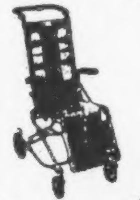
New Lightweight

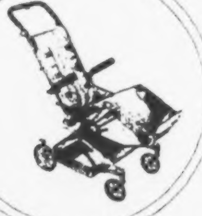
Tilt Chair

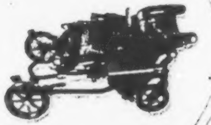
Compact Folding

Looking for a compact, yet lightweight tilt chair? The Rodeo tilt-in-space chair is just that, it has 10 - 45° adjustable tilt and a seat-to-back angle adjustment from 90 - 105°. Key features include an adjustable height handle, angular adjustable footplate, elevating legrests and an optional tray located under the chair for storing medical necessities/auxiliary equipment. The seat depth is adjustable allowing for years of use, and a wide variety of comprehensive positioning options are also available.

Call **1-888-CONVAID** today for your free brochure and product video. Or visit us online at **www.convaid.com** for more information.







Convaid MADE IN THE U.S.A.

www.convaid.com

PO Box 4209, Palos Verdes, CA 90274 USA • Tel 1-888-CONVAID (266-8243) / FAX 310-618-8811

Circle #25 or visit www.eparent.com/adinfo

HARD MANUFACTURING

AGE APPROPRIATE BEDS

For when your child passes the crib stage!

Dianna Fitzgerald & Her Son Nicholas

The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs, as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

1240

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #38 or visit www.eparent.com/adinfo

EP

has the information an "Exceptional Parent" like you needs

EP
Exceptional Parent

Your paid subscription includes the EP

2003

Annual Resource Guide,

which normally sells nationally for $19.95.

This invaluable reference tool is a "must-have" for exceptional parents

Save $5.00

by ordering on-line at:

www.eparent.com

For telephone orders call:

877-372-7368

Circle #199

Subscribe and be part of a network of "Exceptional Parents"

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ____________________ Exp. Date __________

Name ____________________

Address ____________________

City ____________________ State __________ Zip __________

E-mail ____________________ Yes, I want more information to help me everyday.

Signature ____________________

BNOV2

Subscribe and be part of a network of "Exceptional Parents"

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95 ☐ 2 Years (24 issues) $65.95 ☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year. Other foreign countries $57.95 per year.

Order by phone toll free 877-372-7368 or Save $5.00 order off the Web: www.eparent.com

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ____________________ Exp. Date __________

Name ____________________

Address ____________________

City ____________________ State __________ Zip __________

E-mail ____________________ Yes, I want more information to help me everyday.

Signature ____________________

BNOV2

Make someone a part of a network of "Exceptional Parents"

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $39.95

☐ 2 Years (24 issues) $65.95

☐ 3 Years (36 issues) $97.95

US funds vary. Canada $54.95 per year.

Other foreign countries $57.95 per year.

PLEASE SEND MY GIFT OF EP TO:

Name ____________________

Address ____________________

City ____________________

State __________ Zip __________

THIS GIFT IS FROM:

Name ____________________

Address ____________________

City ____________________

State __________ Zip __________

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number ____________________

Exp. Date ____________________

Signature ____________________

1241

Save more money: Order off the Web: www.eparent.com

XNOV2

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

1242

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others who are providing a richer life for themselves and for their children.

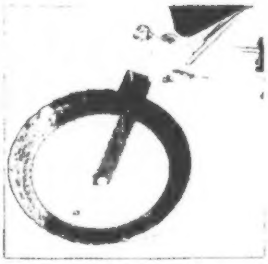
Exceptional Parent's MISSION

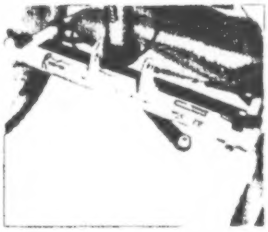
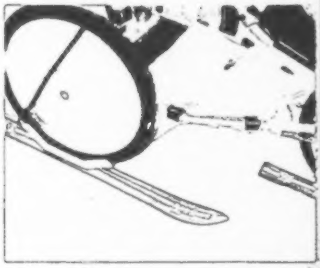
IS TO BE THE PREMIER
INFORMATION
SOURCE FOR PARENTS
EDUCATORS AND
HEALTHCARE
PROFESSIONALS
DEDICATED TO CARING
FOR CHILDREN AND
YOUNG ADULTS
WITH SPECIAL NEEDS
Don't miss a single issue:

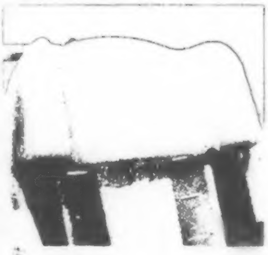
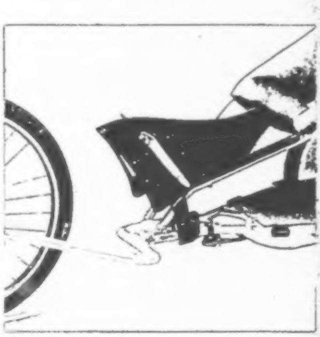
SUBSCRIBE TODAY AND
RECEIVE THE 2003
RESOURCE GUIDE
GO ONLINE AND
SAVE EVEN MORE

EP
Exceptional
Parent

www.eparent.com



The KANGOO

Imagine a product that lets you jog with your child through a park, take her for a bicycle ride through your neighborhood, or let him experience the joys of cross country skiing...You've just purchased a Kangoo, the only mobility base that provides these opportunities. The Kangoo allows your child to experience the outdoors like no other product.

The Kangoo easily folds to fit into the trunk of your car or store in the closet. Made from high-grade aluminum, it is light enough for anyone to handle, and durable enough to provide many years of use. A high quality shock absorber provides optimum comfort for your child even when traveling over the roughest of terrains, and the high quality wheels and axles require minimal effort to push the Kangoo.

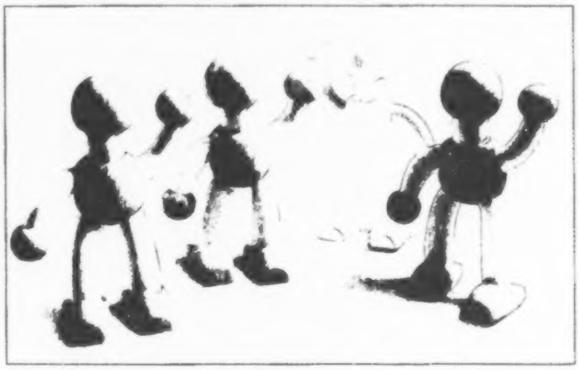
CALL SNUG SEAT NOW FOR YOUR FREE CATALOG

1-800-336-7684

Circle #42 or visit www.eparent.com/adinfo

SNUG SEAT®

NEW TOY FOR ALL



Roundheads, created by Roundheads Worldwide, is a new line of safe and simple toys for children of all ages. These pose-able foam figures are the end product of five years of research, development and market testing, and are now available in stores nationwide. The toys come in a variety of figures, from adult Roundheads, to the soon to be added Roundkids and Roundthings, which include the flying Flapdoofus and turtle-like Tortoogus. For more information on Roundheads, Roundkids, or Roundthings, contact Roundheads Worldwide, 203 Main Street, Suite A-187, Flemington, NJ, 08822 or visit their web site at www.roundheads.com.

Bike Expo and Sports Jamboree

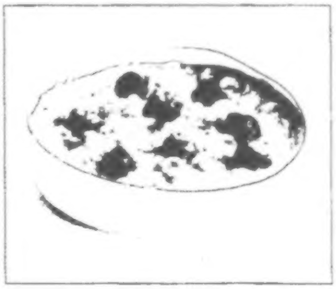
More than 30 different specially modified bicycles were featured in the Bike Expo and Sports Jamboree in Minneapolis, MN on September 21, 2002. Two organizations, both with the mission of empowering people with disabilities to reach their full potential, paired together to sponsor the event. Gillette Children's Specialty Healthcare is a not-for-profit hospital in St. Paul, Minnesota with clinics in Minnetonka, New Brighton and Northern Minnesota. It focuses on individual long-term healthcare needs. Courage Center is a non-profit organization providing rehabilitation, enrichment and independent living services for people with disabilities. The event highlighted bicycles designed to best-fit people's needs that are not available in mainstream stores. Among the units displayed were three wheelers to help stability and handcycles for people with no leg use; others had velcro foot straps to assist those with limited muscle control. Also shown were alternative seats, belts, handlebars and steering devices. Other demonstrations of adapted sports were held at the event including archery, martial arts, swimming and wheelchair basketball.

New Information Outlet Now Available

The National Council on Disabilities (NCD) has created a new electronic informational list to assist with issues such as affordable housing, employment, transportation, healthcare, education and assistive technology. The NCD is an independent federal agency that takes pride in reaching out for equal opportunities to individuals with any kind of disability. To receive approximately five emails a month of helpful information simply send a blank e-mail to: add-bulletin@list.ncd.gov.

Adaptable Products

Ableware makes everyday items such as this scooper plate with suction cup base. It is specially designed to assist individuals with limited muscle control. The high, curved rim makes it easier for a child to spoon feed him or herself. The bottom of the dish has a rubber suction to prevent the dish from sliding. For more information visit http://www.ableware.com.



continued on page 22

LAWYERS INCORPORATED, P.C.

AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

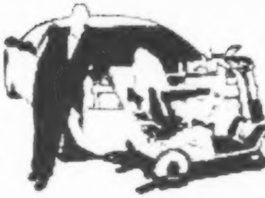
Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #46 or visit www.eparent.com/adinfo

continued from page 20

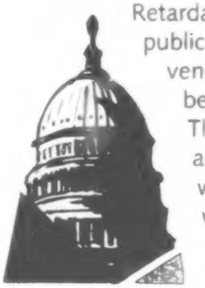
New Advanced Interior Scooter and Wheelchair Lift Hits Market



Vintage Mobility International launched a new interior scooter and wheelchair lift called the Excel 200. It has more advanced features than most other mobility devices, is adjustable in five different places, enabling it to fit in both large and small vehicles, and is accessible to city parking. The Excel 200 is the only mobility machine in its class that can perform curbside parking. Inside the house, the chair or scooter lifts automatically. For more information visit their website at www.vantagemobility.com

Forum on Developmental Disabilities in Washington, DC.

The Administration on Developmental Disabilities (ADD) will hold an ADD Commissioner's Forum at the Mayflower Hotel in Washington, DC from February 18th through the 20th, 2003. Here, representatives from the American Association of Mental Retardation (AAMR), the ADD, and other public and private organizations will convene to discuss issues affecting members of the special needs community. These include the quality of service and support provided to individuals with developmental disabilities, as well as the lack of qualified direct support professionals.



In addition, members of the ADD are interested in hearing about particular programs throughout the country that successfully deal with the issues at hand, so that these programs may be highlighted throughout the forum. The programs may be nominated under either the Quality Management or Workforce Development categories or both. For more information, you can contact either Sue Suter of ADD (202-401-6300), or Steve Eidelman, Executive Director of the Arc, at eidelman@thearc.org (301-565-5469).

Caregiver Story Project

The National Family Caregivers Association (NFCA) is launching a Caregiver Story Project. They want to hear from family caregivers, professionals, parents of special needs children and those involved with elder care. The goal of the project is to provide a forum for all caregivers to let others understand what their lives are truly like, discuss issues and share concerns. To submit a story visit http://www.nfcacare.org click on the story project icon and follow the instructions. You can also view sample stories.

COMMUNITY SURVEY

The Rosalynn Carter Institute for Human Development (RCI) is an organization centered on studying the components of a quality caregiving community. Recently, RCI decided to start up a survey where people can present their ideas on what such a community may entail. In order to contribute to the survey, log on to the RCI web site at http://rci.gsw.edu/CommunitySurvey. For more information, contact Ronda C. Talley, Executive Director & Professor at the Rosalynn Carter Institute for Human Development, Georgia Southwestern State University, 800 Wheatley Street, Americus, GA 31709, or call 229-928-1234.

3rd Annual World Congress and Exposition on Disabilities Honors Ridgeway School

Ridgeway Elementary School was honored by EP Magazine at the 3rd Annual World Congress and Exposition on Disabilities. The award for Educational Institute of the Year was presented at the closing ceremonies of the event in recognition of the schools great achievements in the education of students with disabilities.

CALENDAR

DECEMBER AWARENESS

DECEMBER 1, 2002 WORLD AIDS DAY
American Association for World Health
(202) 466-5883
www.aawhworldhealth.org

DECEMBER 1-7, 2002 NATIONAL APLASTIC ANEMIA AWARENESS WEEK
Aplastic Anemia and MDS International Foundation
1-(800) 747-2820
www.amds.org

SAFE TOYS AND GIFTS MONTH
Prevent Blindness America
1-(800) 331-2020
www.preventblindness.org

The Medical Nutrition hospitals trust. Delivered to your door by someone you trust.

RECOVER
Strengthen the Immune System For A Faster Recovery
DIABETISHIELD

Welcome to the *NEW* Resource® Medical Nutrition Center -
exclusively at www.resource.walgreens.com

Now you can have Resource® Medical Nutrition supplements that hospitals trust - conveniently shipped straight to your home by Walgreens, *The Pharmacy America Trusts®*.

Clinical performance, great taste

Health Care Professionals recommend Resource® Medical Nutrition because it works, but you'll choose Resource® for the way it tastes. All our products come in easy-to-use packaging, making Resource® as simple to enjoy as it is to obtain.

Our prices go down easy, too

Resource® Medical Nutrition products are priced competitively with other brands, and standard shipping is FREE on orders of $50 or more*. Plus, we'll rebate 50% off of one order, up to $20**.

Order now

Visit **www.resource.walgreens.com** or call **1-800-828-9194** to place your order or request a program catalog. You'll discover we not only promise the best Medical Nutrition - we deliver it.

NOVARTIS

NOVARTIS NUTRITION
To improve lives. To extend lives. To save lives.

Walgreens.com®
America's Healthiest Web Site™

We offer Resource® Medical Nutrition for the following health conditions:

General Nutrition Supplements • Before/After Surgery • Cancer • Children's Nutrition • Diabetes • Digestive Conditions • HIV/AIDS • Fluid Restriction/Concentrated Nutrition • Kidney Disease/Dialysis • Pulmonary (Lung) Conditions • Swallowing Problems • Wound Healing

As always, consult a Doctor or Dietitian regarding Medical Nutrition support.

Circle #51 or visit www.eparent.com/adinfo

*Subtotal excludes prescriptions, taxes and shipping
**Novartis Nutrition mail-in rebate offer

Not available in Walgreens stores.

©2002 Novartis Nutrition Corporation

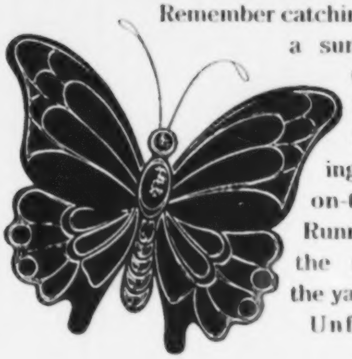
Recapturing the Joy

Finding Fun and Enjoyment in Each Day!

by Patricia J. Brown, Monica Uhl, Jill Baughan

"People tell me I'm handling all this so well," said Meg. "They have no idea that I just put on my 'happy face' when I leave the house. To be perfectly honest, there are days when caring for David so overwhelms me that I don't even want to get out of bed. I just want to take a vacation back to the days when I had no worries, no cares—nobody to think about but myself."

Who among us hasn't longed for that total abandonment of time and responsibility, even if it's only for a little while? How often do we as adults take time to really let go, relax and play? Remember catching fireflies on a summer night? Going to birthday parties and playing Pin-the-Tail-on-the-Donkey? Running through the sprinkler in the yard?



Unfortunately, these are only memories for most adults. Many of us have lost—or at least neglected—the art of playing and the joy of spontaneity, and it's no wonder. Parents of children with disabilities have an endless list of "things to do;" not only must we care for the child with a disability, but also for other children, and maybe even aging parents. Not only must we make a living, but also maintain a household and all the relationships within that household. And these days, voice mail, e-mail and cell phones—all designed to save us time and energy—often instead create a sense of urgency in our lives that makes it even harder to keep up. Too many things demand our time, and we don't have a minute to waste. It's not surprising that getting respite from our caregiving responsibilities seems impossible to accomplish!

Guilt also keeps some folks from taking a break—guilt that may come from leaving a child with a disability in someone else's care. But Susan, mother of seven year-old Wayne and three younger children, says, "I hire a sitter one day a week. I may not be gone for the whole time, but I may run, shop, meet a friend for lunch. And the time I spend away from my child makes me a better mother when I come back."

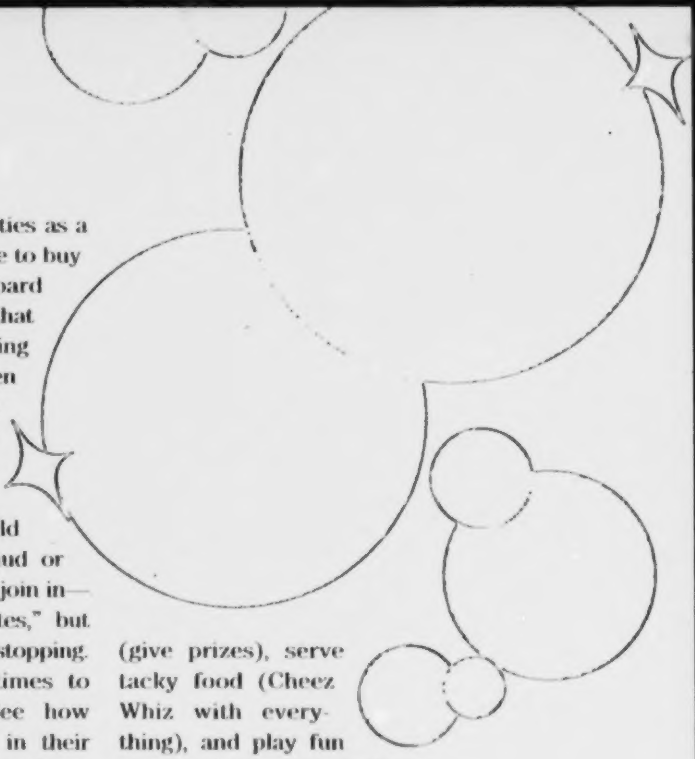
Certainly this time away is important—even vital—to maintaining a sense of self. But there's still another reason to develop a daily habit of play, with and without your child, and that's to deal with the stress of a major life change. Your life may have been ordinary a few years ago. Then your child was born, things were not as expected and all your idyllic dreams of parenthood evaporated as reality stormed in:

Endless appointments with doctors and teams of professionals. Will this ever end? I'm the parent. Why do I feel like the one with the least control here?

The medications. Am I giving him the right amount? Is she getting this at the right time? What if he has a negative reaction?

Educational planning. I never

1248



heard of an individualized education plan before; now all I hear is IEP.

Talk of respite. I really do need a break from all of this, but how? When?

The countless details that can pull the most positive person into a negative hole.

The stresses that accompany such a major life change can even be detrimental to your health. Negative thoughts and feelings can suppress the production of endorphins in your body, and thus make you more susceptible to illness. And over time, these same negative thoughts and feelings can convince you that life is nothing but serious.

Caregiving issues have become so important to so many people caring for children with special needs, ill family members, or aging parents that the National Family Caregivers Association was developed to focus on just this issue. The NFCA stresses the importance of self-care so caregivers stay healthy, physically and mentally. Caring for yourself can help you be a better caregiver, while also helping you to recapture joy in your life. Self-care includes remembering that there can be a lighter and more joyful side to life. Learning how to develop a playful attitude can help you take the time and break you need. Here's how:

Let Go of Time

Ironically, you might have to plan a specific time to let go, but so be it. Don't be afraid to block off a period and intentionally forget your watch. Or decide to relax and play until you're really ready to quit. This can work especially well if you choose activities as a family. Susan makes sure to buy a couple of active board games with simple rules that the whole family, including Wayne, can enjoy. Then her family spends one evening a week playing for as long as the children want.

Similarly, if your child wants to play in the mud or dance around the house, join in—not for "just five minutes," but until you really feel like stopping. Take a moment sometimes to watch little ones. See how absorbed they become in their own play, and you'll find that it really is possible to suspend time, even if just temporarily.

Be Spontaneous

So maybe it has been a while since you dusted under the bed. Or your schedule may dictate that you've got to clean the house. Society may pronounce you "too old for that stuff" when you act on a desire to turn cartwheels in the yard. But spontaneity, another prerequisite of play, has its own reward: liberation.

Try to respond to the voice that's telling you what you really want to do, with or without your child. Blow bubbles or fly a kite; go to the library and drink in the silence; go out to breakfast alone and savor that second cup of coffee; take a scenic drive on your way home. Indulge your whims and explore your creativity. Invite some friends over for a no-stress evening.

Celebrate a birthday—or any day—with a Tacky Party. Encourage guests to wear the tackiest clothes they can find (give prizes), serve tacky food (Cheez Whiz with everything), and play fun and physical games such as Hide and Seek or Name That Tune. You can have a basic plan for an evening and still be open to a lot of surprises!

Maintain a Sense of Humor

This should make it easier to keep your sense of humor, a third precursor to play. If you've forgotten or you're out of practice, it's necessary to relearn how to be silly. And if you're afraid of looking foolish when you're acting silly, consider this: much of play's therapeutic value comes from a childlike vulnerability that delights in the absurd. As long as you're having fun, who cares if you look goofy?

So go ahead. Dress up like a leprechaun on St. Patrick's Day or like Cupid on Valentine's Day. Sing on someone's answering machine. Walk in the rain with your bathing suit on (fun for singles, married people, families and entire neighborhoods). Once you get the hang of being silly, it may become second nature to

continued on page 26

continued from page 25

you and, at least for a while, you can take yourself lightly.

Your home can even reflect and encourage your sense of humor. Try setting up a "humor corner," an area where you post cartoons, pictures, stories—anything that makes you smile. Or decorate with humor. Lay a pair of "Groucho" glasses in the bathroom that everyone (especially visitors) uses. You'll be surprised at the number of people who emerge from the bathroom in those glasses. Be sure to take a picture of everyone that does, and start a photo gallery in your humor corner. Martha Stewart may not be impressed, but she's probably not a regular at your house anyway.

Take Some Risks

Finally, playing might well involve trying something new, so don't be afraid to take some risks. Be a participant, not a spectator. Helen, for example, has a son who is old enough to be in the youth group at church. However, he is far behind the other teenagers in emotional and intellectual maturity. In search of a way to help with the group and at the same time find a place for her son Chad, Helen enrolled in and graduated from clown college and led the clown ministry, which included her son.

Is there something you've wanted to do but never felt you had the time to pursue? Canoeing? Rock climbing? Backpacking? Writing? Maybe you'd want to take a class or, if that's too much of a commitment, a workshop in an activity that would be pure pleasure for you. And remember, you don't have to be good at something to have fun doing it.

Keep a Positive Attitude

One final requirement for a playful mindset is an upbeat attitude. Granted, this is easier said than done. But try this: At the end of each day, in a special notebook designated for just this purpose, take five minutes to write down a few of the day's pleasures. Sometimes this takes some serious digging, but even the worst days have their redeeming moments: a soak in the tub, extra cheese on your pizza, "I love you" in word or deed from someone you care about. Especially during low times, there's something very healing about filling an entire book with the rightness of life. Then make a list of ways you'd enjoy playing (by yourself, with your spouse and with your family), post it somewhere visible and make sure to play a little every day. It's true that hanging a spoon off the end of your nose won't make life trouble-free, but finding the fun stuff in life might give you a lift and make this business of living just a little more joyful. **EP**

Dr. Patricia Brown is the associate dean for academic programs at the School of Continuing Studies, University of Richmond in Richmond, Virginia. Pat is the mother of a 25-year-old son, Patrick, with Cri Du Chat syndrome and has dedicated her life to empowering people with disabilities. She has published articles, chapters, and given speeches in the United States and Brazil. She recently won the Bonner Scholar Story Award at the University recognizing her work toward the elimination of discrimination against people with disabilities.

Monica Uhl is the Project Director for the Respite Resource Project at the Partnership for People with Disabilities, a university center for excellence in developmental disabilities at Virginia Commonwealth University in Richmond, Virginia. She grew up with a sister with special needs and has worked in Virginia and Connecticut for over 22 years with various disability organizations.

Jill Baughan is an adjunct instructor of English at Virginia Commonwealth University. She also works as a worship assistant at Cool Spring Church in Mechanicsville, VA. She is currently working on a book that encourages people to relearn the value of play. She lives in Mechanicsville with her husband and spends most of her time trying to figure out how to turn work into play.

They Have A Lot to Say...

and you can be the one to help them say it.

Since 1983, DynaVox Systems has been committed to helping individuals with speech, language and learning disabilities to lead fuller, more independent lives.

Our products are a part of a broad group of communication methods called *augmentative and alternative communication*, or AAC. DynaVox AAC devices help thousands of young people with speech disabilities due to cerebral palsy, autism, mental retardation and Down's syndrome to express themselves.

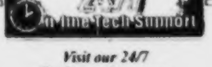
As the AAC industry leader, our success is based on a strong partnership with our customers. Our foremost objective is to ensure that our customers receive the best solutions to meet their immediate and long-term communication needs. This is enhanced by a comprehensive network of support services including:

- ***Funding Assistance***
- ***Product Training and Support***
- ***Expert Field Support***
- ***Telephone Customer Support***

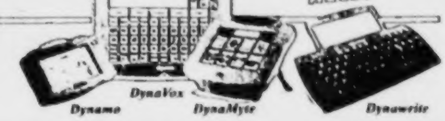
All DynaVox associates are committed to the development of innovative services. Together we can achieve our goal as we continue to improve the lives of individuals with speech disabilities by bringing them the power of communication.

FREE!

DynaGuide Training CD included with the purchase of a DynaVox 3100, DynaMyte 3100 or Dynawrite.



Visit our 24/7 On-line tech support at www.dynavoxsys.com!



DYNAVOX
a division of
SUNRISE MEDICAL

inTouch with Communication Solutions for Life.

For more information please contact our inside sales department at:

1-888-697-7332

www.dynavoxsys.com

Circle #29 or visit www.eparent.com/adinfo

The Healing Powers

By Laura Apel

There is a cliché that laughter is the best medicine,

but Sherry Dunay Hilber and RX Laughter are proving that it just may hold true.

RX Laughter is the first project ever to use humor as a healer for children and adolescents being treated for serious conditions such as cancer, cerebral palsy, congenital orthopedic problems and burns. A national non-profit research, therapeutic, entertainment and health-education organization presently in its third year at the UCLA Jonsson Cancer Center, Mattel Children's Hospital and the Neuropsychiatric Institute and Hospital, it was founded by former primetime television network executive Sherry Dunay Hilber. She wanted to use her experience in overseeing comedy programs to help the seriously ill.

Such stars as Emmy award winner Ray Romano from CBS' "Everybody Loves Raymond," Kevin James from CBS' "King of Queens," and comedians Wendy Liebman and Steve Mittleman supported this effort by performing in September at the Comedy Central Benefit for RX Laughter at UCLA.

As Hilber explains, "I have always believed that comedy programs are an emotional and physical healer." She took this idea and chose the UCLA School of Medicine because of their reputation for finding innovative ways to integrate emotional healing into the medical environment.

RX Laughter relies on very basic human tendencies and emotions. Funny videos of carefully selected television shows and films are integrated into the medical environment and are shown to children and teens undergoing medical procedures. The basic concept is to improve immune system functionality and speed of healing, reduce incapacitating pain, alleviate stress and improve the patient's quality of life. Severe anxiety, fear and isolation, common feelings among these patients, are addressed.

The videos are prescribed as a part of the individual medical plan utilized for the patient and research has shown that a positive attitude can provide a better chance of recovery. The American Medical Association briefing of February 21, 2002 reflected this in its statements that children and teens are better able to withstand painful procedures as they watch and laugh at the funny programs.

Two UCLA pediatric cancer researchers and physicians, Dr. Margaret Stuber and Dr. Lonnie Zeltzer, became great supporters of the organization, and with Comedy Central as seed funder, with $75,000 for the first two phases of a five-year study, the project is moving forward.

The success of the program overall is due to the merging of its three different components:

✲ THE RESEARCH COMPONENT

The main goal of RX Laughter is to help children and their families better deal with treating life-threatening illnesses. There is a concentration on examining how the immune system performs in response to the tapes: in short, seeking clues as to how the child can heal better and with less pain through the use of laughter. The doctors' research centers on whether natural killer cells in cancer patients can be improved to

# of a Good Laugh

enhance the body's ability to fight tumors and whether there is a correlation between the degree children watch the tapes and the buildup of their immune system. The research explains which kinds of humor, for which patients, under which circumstances will aid in pain management, improve immune function and reduce overall stress and anxiety.

* THERAPEUTIC ENTERTAINMENT COMPONENT: THE RX LAUGHTER HOSPITAL NETWORK

This component works in conjunction with the research component because, as the information is gathered on how humor can improve various functions and healing abilities, these findings are then applied and put into use through the RX Laughter Hospital Network. The goal here is to make the hospital experience less frightening or stressful and more manageable for both the patient and family. The Network carries comedy programs that have been shown to be both physical and emotional healers.

* COMEDY HEALTH EDUCATION COMPONENT

Because most children undergoing serious procedures and treatments are not intellectually or emotionally capable of truly understanding their illnesses or subsequent treatments, it becomes an even greater challenge for them to obtain the motivation needed to heal. When standard health education videos are used to inform the young patients, researchers have found an uncaptivated and disaffected audience. However, when specifically produced Comedy Health Education Videos are utilized, the children are entertained and simultaneously, educated about their particular illness. The videos are constructed from the perspective of the patients so that they are learning about their own illness and treatment plans through the words and thoughts of others just like them.

The RX Laughter organization has already made great strides in the medical world through its research and projects. The latest findings have shown that healthy children have a greater ability to withstand painful medical procedures longer and with less overall stress and anxiety as they watch the chosen videos. The therapeutic effects alone constitute a great success for the program, as both the children and their parents have found the incredibly difficult experience of treating these illnesses somewhat assuaged by the humorous videos and the act of laughter.

Dr. Stuber believes in the RX Laughter project and the benefits that humor and comedy can have on treating illnesses. She feels that the parents, as well as the children, can truly find comfort and hope in the act of laughing. As she recommends to the many parents who are forced to deal with the pain of having a child who is seriously ill, "Try to laugh with your child. Use laughter to get out of a confrontation or a grim moment. It will make both of you fell better. Laughter may indeed be the best medicine."

To give a donation to the RX Laughter program or to learn more about the organization, please visit www.rxlaughter.org., or call 310-206-3932.

Comedians from opposite, top; counterclockwise: Steve Mittleman, Ray Romano, Wendy Leibman, Tom Ker and Kevin James.

the Land of Oz:

Parents'

for Managing Life

By Kate Scorgie, PhD and Lorraine Wilgosh, PhD

n her book *When the Heart Waits*, Sue Monk Kidd portrays Dorothy's journey in *The Wizard of Oz* as an allegory for overcoming life crises. Until the tornado came, all Dorothy had ever known was her simple life in Kansas with Toto, Aunt Em and Uncle Henry. When the devastating event occurred, Dorothy was catapulted from her familiar surroundings to the often-bewildering Land of Oz.

The remainder of the book was the story of Dorothy's profound longing for her home and her subsequent wanderings through Oz in order to find it. Dorothy was told that the way home would involve a very long journey, "through a country that is sometimes pleasant and sometimes dark and terrible." Kidd reminds us that at some time in our lives, each of us will encounter a "tornado" experience and, like Dorothy, we may find ourselves in a strange land with no road map and few recognizable landmarks, longing for our former, familiar lives.

Dorothy navigated her way through Oz with the assistance of three new friends she met along the way: a Scarecrow who needed a brain, a Tin Man looking for his heart and a Lion seeking courage. Kidd claims that these characters are sent to remind us that in the midst of any life crisis, what each of us needs for safe navigation "home" is a new way of thinking, a new way of feeling and a resolve to persevere.

For the past several years we have been talking to parents about their journeys in parenting a child with a disability. We began by conducting extensive interviews with 15 parents whose children have a variety of conditions. As they narrated their journey from the initial diagnosis to the present, we asked them to share specific strategies they found effective for managing their personal and family lives. We then developed a survey instrument that we sent to two larger groups of parents. We asked them to indicate how important each of the strategies mentioned by the first group of parents had been to them as they parented their children. In particular, we were interested in documenting life management strategies that were deemed effective by the large majority of parents, regardless of child age and disability.

Parenting a child with a disability is an adventure. Each day brings about another challenge and another test that pushes the limits of ones ability to persevere. It is when these trials are overcome and the successes, no matter how small, are accumulated that entire families find the strength that they need to continue. These lives are truly inspiring.

We have collected information from more than 200 parents. They described how the diagnosis of disability catapulted them into a bewildering new world. They shared the things that both helped and hindered them along the way. And they spoke powerfully of how, through the years, they have developed new ways of thinking, new ways of feeling and a determination to stay the course.

After analyzing these stories, we were able to document a number of strategies that parents held in common. We call these the Top Twenty Strategies for Effective Life Management, and would like to share them with you through the words of parents.

"My advice to a parent of a child newly diagnosed is, first of all, just to celebrate the birth of this child. Just to enjoy this child…because everyone else will try to give him a label." [mother of a nine-year-old son with severe multiple disabilities]

Choose to focus on what's going right

"I dwell so much on the positive that you would think Ryan was actually pretty high functioning, [though] he's very, very limited in what he can do. But I don't look at those things. I think it's much easier to celebrate the little successes and sometimes they're minuscule. You have to look at the positives and the little successes and dwell on those." [mother of a nine-year-old son with autism]

Get beyond the "why?" to the "how?"

"If we could all just accept our kids and teach them they're pretty great just the way they are… the sooner you do it the better it is. Pretending like they're gonna get well later—oh, I went through that phase. It was always some miracle that was going to happen. But that's all dead time, all 'no growth' time for you and your child. So the sooner you can say, 'This is how it is. Let's go forward from here,' the better it is for everyone!" [mother of an adult son with profound hearing impairment]

Appreciate what your child contributes to others

"Last year one of Jana's friends wouldn't go to Brownie camp unless Jana went. This friend's mother phoned me, desperate, weeks before camp: 'Jana's not getting sick, is she? She's still going to go, isn't she? Because my daughter will not go without Jana.' And so we learned that Jana is a support to her friends, she does contribute. And those are the things we needed to start looking at." [mother of a nine-year-old daughter with Down syndrome]

Trust your instincts

"After two years [of preschool] I felt very frustrated. I used to leave there crying, thinking, 'Why are you letting them do that to him and treat him like that and talk to him like that?' But slowly I developed the confidence to decide I don't have to be this way any more! Now I think there's nothing that I couldn't do if I set my mind to it." [mother of a nine-year-old son with autism]

Don't go it alone; ask for help

"I needed to take my daughter to another city for treatment and we didn't have the money to pay for the airline tickets. I was moved to phone our minister—I'd never, ever asked for help from this church before, but I called and explained our situation. They were able to give us some financial help. And the minister phoned down to some families in that city and asked if someone could meet us. So a couple met us at the airport. They put their arms around us and kept them around us six whole weeks. And when we came home I realized that it wasn't Mandy who had had the healing, it was me. And it sort of turned my thinking around; I learned that you don't get help unless you ask for it. As long as people think you're okay, they leave you alone." [mother of a 17-year-old daughter with moderate developmental delay]

Reassess success

"You have to learn to come up with your own definition of what a successful child is, and not bow to the theory that the successful child is going to grow up, get married, have a good job and do this and that. You have to say, 'Well, for our child it will be different. For him success might be something else.' You have to throw out the old definitions. As long as he's happy at what he's doing, why should we define [what] happiness [is]?" [father of an eight-year-old son with pervasive developmental delay]

Utilize planned perseverance

"I spoke with a resource person and she said, 'Every year you're going to have to address the same issues: Who's going to be the teacher? What kind of support is there going to be and will that be sufficient for my child? Every year you're going to have to address this. Just put it on the calendar.'" [mother of a six-year-old son with an undiagnosed genetic condition]

Be a parent first

"There's one thing I'd do differently now. When we found out Jeremy was hearing-impaired, I signed up for a course, 'How to work with your hearing-impaired child.' And all of a sudden I turned into his teacher instead of his mother. But finally, a few years ago, I just woke up and said, 'I'm sorry. I'm not doing this. I'm not going to sit across from the table and force him to do this. I'm just going to practice being his mother.' And I'm much happier. I feel it was like a weight lifted off me." [mother of an 11-year-old son with cerebral palsy and profound hearing impairment]

Keep your sense of humor

"The stories about Nathan have become family tradition. Lots of families have stories that they tell and retell. But the Nathan stories in our family are the funniest—he's just hilarious. Oh, there have been lots of stressful times. For every funny story there are probably 10 or 20 difficult stories—stories of challenges and trials. But it's the funny stories that keep you going." [mother of an 11-year-old son with Down syndrome]

Be flexible day to day

"Because of her illness, how Laura feels fluctuates a great deal. So I wrote a list called White Days, Gray Days and Black Days. On 'white days' [the good days] I might go to the park, go out, cook dinner, make the most of a day when Laura's feeling well and has some energy. 'Gray days' [in-between days] I still put things on my list, like cook supper—but it's more like sit and watch a video with Laura, read books, or go to work, as she can still go to the babysitter on gray days. On 'black days' when she's really ill, we might order pizza or, if there are plans, change them." [mother of a seven-year-old daughter with degenerative metabolic disorder]

continued on page 32

continued from page 31

Give yourself a "time out"

"I have one night a week and it's mine. I need it. I always have something to look forward to and that's what gets me by. I forget about everything for an evening and go out with my girlfriends. I know none of them can relate to what I go through. They have stress and they have so-called 'normal' kids. If they need one night out a week, I probably need three. But, yes, I just go out and try not to worry about it that night, and somehow the next day it doesn't seem that bad." [mother of seven-year-old triplets with moderate to severe developmental disabilities]

Allow yourself "ups" and "downs"

"Even though I say I have accepted everything that has happened with Jason—yes, I have accepted it. But there are always times when I will hear a song on the radio and all of a sudden it will hit me, 'He's never going to hear that exactly like I do.' I will go through the grieving process again, and I will cry. And then away I go and I'm okay. I think this is just a life-long thing. He's going to be my baby even when I'm 80 years old. And I think it's okay to give yourself permission to keep feeling." [mother of an 11-year-old son with cerebral palsy and profound hearing impairment]

Remember to nurture your marriage

"Court your wife. You know she's going to be stressed out, and so will you, and you will need each other. Do what you need to find time to be with each other. Go to dinner—go to a movie—do whatever you want to. Find time when you can be away from the demands and just be together." [father of a 12-year-old-daughter with severe developmental delay]

Be a family

"As a parent, you have to set an expectation to make things happen. One thing we do is go to a lodge in the mountains. The whole family goes, and you think, 'Yes, we can still do things as a family.' And we've always insisted that we eat breakfast as a family. Sometimes our kids complain, but I think it's important to be together as a family." [mother of a nine-year-old son with severe multiple disabilities]

Balance time together with each of your children

"My son once said, 'You really do like Tommy much better than us, don't you?' I asked why, and he said, 'You're always spending time with him and you're always holding him.' Well, one thing an experience like this does to you is to make you think consciously about a lot of things you never thought about before, like spending time with your other children. And I guess it's not being afraid to talk to your kids about the situation, either." [mother of a nine-year-old son with multiple disabilities]

Know what you want and go for it

"I think the ability to problem-solve is very valuable. Don't take 'no' as a final answer; take it as a definite 'maybe' and go from there. A lot of times they say 'no' because they think you're going to go away. What you need to do is try to analyze the situation. If you do your homework, are well prepared, and make a legitimate argument, oftentimes people will listen." [mother of a 25-year-old son with Coffin-Lowry syndrome]

Be resourceful; find ways to be understood

"A neighbor came in one morning and we spent a morning taping Rachel in spasm, just to show the work that was involved in caring for her. We did it for the medical profession, because they couldn't understand my story. So I have it on video. I have shown it to social workers, too, and I think it would be a good tool for group homes so they can be prepared for the kind of help needed." [mother of a 17-year-old daughter with moderate developmental delay]

Connect with other parents

"I feel it is extremely important that parents of children with disabilities make contact with each other, because there's nothing like speaking with somebody who's in the same boat. There's something that draws us all together. If I'm having difficulty with something, I will not call the professionals. Other parents are the first people that I will call. I will ask another parent, 'Did you have to deal with this? How did you handle it?'" [mother of 11-year old son with cerebral palsy and profound hearing impairment]

Value the journey

"When I look back I realize my son has been a wonderful teacher to me. He's had an impact on so many lives—that's the wonderful part. When Chris was young I used to think I had to know [right now] everything he'd need to know. In time I learned that as Chris grows, I will grow. And I will have the knowledge needed to meet his challenges. It was very important for me to recognize that." [mother of a 15 year-old boy with Down syndrome]

These are twenty of the life-management strategies most often mentioned by parents in our studies. Every family that participated in our study was diverse, complex and unique, and each employed the strategies in a way that was unique to their family situation. It seems that there are many paths through the Land of Oz, and through working together parents can create useful roadmaps and identify familiar landmarks. EP

Kate Scorgie, Ph.D. is an Associate Professor of Graduate Education at Azusa Pacific University (California). Lorraine Wilgosh, PhD, is a Special Education professor in the Departmentof Educational Psychology at the University of Alberta.

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C. & Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #48 or visit www.eparent.com/adinfo

KEYNOTE SPEAKERS AT WORLD CONGRESS & EXPOSITION ON DISABILITIES EDUCATE AND INSPIRE ATTENDEES

The Keynote Speakers at the World Congress & Exposition on Disabilities, that recently took place on October 3-5, offered attendees inspiring words, practical advice and hope for the future. Each keynote speaker addressed a room of over 1,000 people. The 3rd Annual WCD took place at the Orange County Convention Center in Orlando, Florida.

Opening the keynote series was Robert H. Pasternack, of the U.S. Department of Education, on Thursday, October 3rd at 10:00 a.m. Dr. Pasternack is the Assistant Secretary for Special Education and Rehabilitative Services and serves as principal advisor to the U.S. Secretary of Education on these matters. He also has a lifelong personal experience with people with disabilities, as the legal guardian for nearly 20 years for his brother, who was born with Down syndrome.

Dr. Pasternack's speech addressed "A New Era in Education—The No Child Left Behind Act." He opened his talk with a proclamation from President Bush that announced October as National Disability Employment Month. He said that it was a high priority of the current administration to insure that all citizens should be able to be employed and that disability does not mean "no" ability.

He told a filled room that if people with disabilities want to go to college, they should be able to go to college, and if they want to work they should be able to work. He also stressed that there were other quality of life issues that need to be addressed including lack of housing for the disabled and inadequate transportation. Dr. Pasternack also stressed the importance of technology and improved mental health services in the lives of the disabled.

He concluded with reaffirmation of his commitment to the No Child Left Behind Act and with helping the more than 50 million people in the U.S. with disabilities.

The Thursday afternoon keynote speaker was given by Jeff Taylor, Founder and Chairman of Monster. Mr. Taylor is recognized as an innovator and a visionary in both the Internet and career industries. Through Mr. Taylor's guidance and leadership, Monster catapulted to the number one position in the online career industry, currently serving over 10 million job seekers each month, and has reinvented the way in which the world looks for employment.

Underscoring the importance of October being "National Disability Employment Month,' Mr. Taylor spoke about the Internet's power to help people with disabilities find jobs and match specific skills with the appropriate employers.

On Friday morning, Francis S. Collins, M.D., Ph.D., a Physician-Geneticist for the National Human Genome Research Institute (NHGRI), part of the National Institutes of Health, delivered a keynote address on "Genomics, Disabilities & the Future." Dr. Collins oversees a complex multidisciplinary project aimed at mapping and sequencing the entire human DNA, and determining aspects of its function. This is considered one of the most important scientific projects of our time.

He said that there are no perfect genetic specimens and estimates that every person carries between 5-50 significant genetic flaws. His organization is committed to studying the genetic componentary of all diseases.

In concert with the 50th Anniversary of the discovery of DNA in 2003, Dr. Collins also anticipates the announcement of bold new research plans for genomics. He also spoke about fulfilling the promise of genomics for better health including medical genomics, functional genomics, comparative genomics and proteomics.

On Friday afternoon, WCD was honored to have Governor Jeb Bush deliver a special address. He reiterated his administrations commitment to ensuring that individuals with disabilities and their families have equal opportunity and access to a meaningful life and a government that serves as part of the solution. He spoke about his initiatives that are focused on community based programs, vocational rehabilitation, assistive technology and about making it easier to get disabled parking passes.

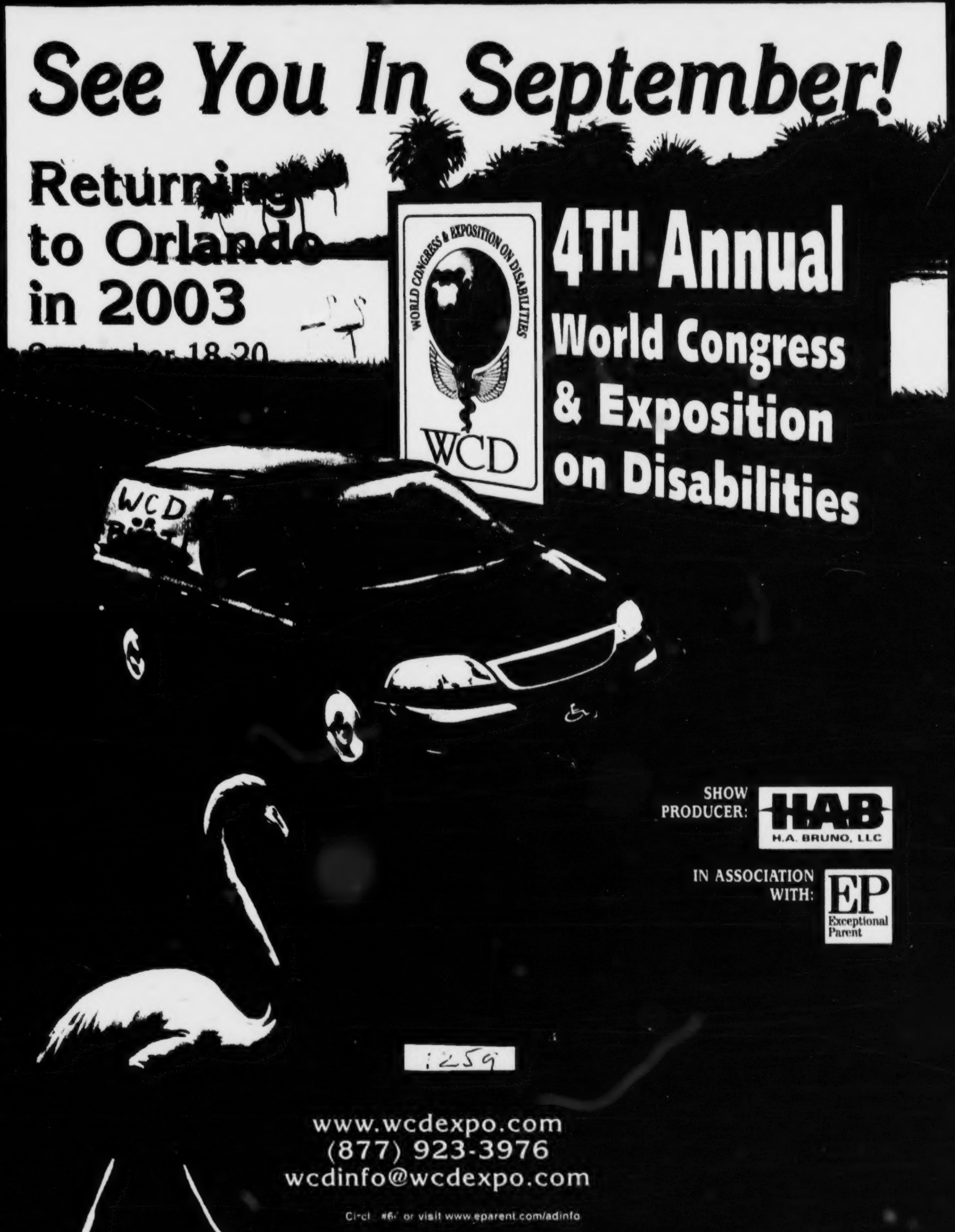
After his speech, Governor Bush spent time with members of the audience including people with disabilities and their family members. He posed for pictures, answered questions, signed autographs and was well received by all the attendees.

On the last day of the WCD event, Saturday, October 5th, General James L. Jones, 32nd Commandant of the Marine Corps presented the final Keynote Address. General Jones illustrious career has spanned over 35 years of serving his country including active duty in Vietnam, Japan, Northern Iraq, Turkey, Germany, Bosnia, and Macedonia. He was promoted to General on June 30, 1991 and assumed his current post on July 1, 1999. The General and his wife Diane Jones are members of the U.S. Armed Forces Exceptional Family Member Program. This program provides assistance to family members of service personnel who have special needs.

General Jones praised the WCD for "Joining One Good Act to Another," by providing hope and a good quality of life. He spoke about the efforts of the military to help people with disabilities and special needs to obtain medical, educational and employment opportunities. He also will continue his advocacy to make political leaders aware of the needs of people with disabilities. General Jones also felt that his work with the military community can transcend to all types of communities.

He concluded with his sincere hope that all the attendees at the WCD would profit from their experience at the event.

Visit www.vwcdexpo.com to view webcasts of Keynotes and other WCD highlights



See You In September!

Returning
to Orlando
in 2003

September 18-20

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

4TH Annual
World Congress
& Exposition
on Disabilities

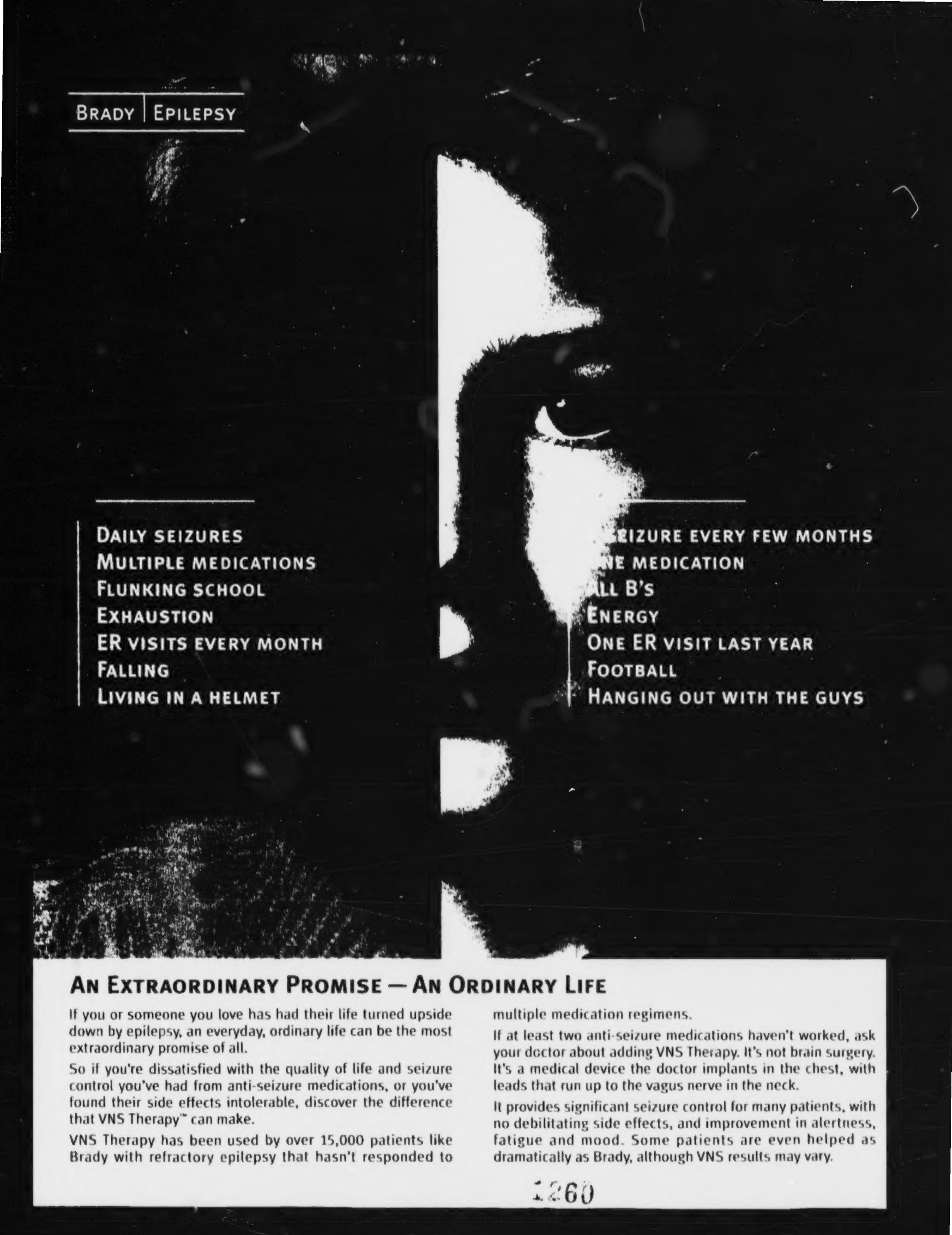
SHOW PRODUCER: HAB
H.A. BRUNO, LLC

IN ASSOCIATION WITH: EP
Exceptional Parent

www.wcdexpo.com
(877) 923-3976
wcdinfo@wcdexpo.com

Circle #6[illegible] or visit www.eparent.com/adinfo

1259



- DAILY SEIZURES
- MULTIPLE MEDICATIONS
- FLUNKING SCHOOL
- EXHAUSTION
- ER VISITS EVERY MONTH
- FALLING
- LIVING IN A HELMET

- EIZURE EVERY FEW MONTHS
- NE MEDICATION
- LL B'S
- ENERGY
- ONE ER VISIT LAST YEAR
- FOOTBALL
- HANGING OUT WITH THE GUYS

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

NCP
VNS
THERAPY
VAGUS NERVE STIMULATION
Cyberonics

BEST COPY AVAILABLE

VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

Circle #28 or visit www.eparent.com/adinfo

EXECUTIVE SUMMARY[1]
SAFETY INFORMATION
FOR THE NCP® SYSTEM

INTENDED USE / INDICATIONS – UNITED STATES

The NCP System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures which are refractory to antiepileptic medications.

CONTRAINDICATIONS

- The NCP System cannot be used in patients after a bilateral or left cervical vagotomy.
- Do not use short-wave diathermy, microwave diathermy, or therapeutic ultrasound diathermy on patients implanted with the NCP System. Diagnostic ultrasound is not included in this contraindication.

WARNINGS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals. This is not intended to serve as a substitute for the complete NCP System Physician's Manual.

⚠ The **safety and efficacy** of the NCP System has not been established for uses not covered in the "Intended Use/ Indications" section of the manual.

⚠ The safety and efficacy of the NCP System treatment has not been established for stimulation of the **right vagus nerve** or of any other nerve, muscle, or tissue.

⚠ **Excessive stimulation** at a combination of high frequency (≥ 50 Hz) and an excess duty cycle (that is, one that occurs when ON time is greater than OFF time) has resulted in degenerative nerve damage in laboratory animals. An excess duty cycle can be produced by continuous or frequent magnet activation (> 8 hours), as determined by animal studies. Cyberonics recommends against stimulation at these combinations of ranges.

⚠ **Aspiration** may result from the increased swallowing difficulties reported by some patients during stimulation. Patients who have **pre-existing swallowing difficulties** are at greater risk for aspiration.

⚠ **Device malfunction** could cause painful stimulation or direct current stimulation. Either event could cause nerve damage and other associated problems. Patients should be instructed to use the magnet to stop stimulation if they suspect a malfunction, and then to contact their physician immediately for further evaluation. Prompt surgical intervention may be required if a malfunction occurs.

⚠ Susceptible patients with predisposed cardiac conduction systems (re-entry pathway) have not been studied as part of controlled clinical trials to establish the safety of NCP system treatment in these patients. Evaluation by a cardiologist is recommended if the family history, patient history, or electrocardiogram suggests an abnormal cardiac conduction pathway. Serum electrolytes, magnesium, and calcium should be documented before implantation. Post-implant electrocardiograms and Holter monitoring are recommended if clinically indicated.

⚠ **Sudden unexplained death in epilepsy (SUDEP)**: Through August 1996, 10 sudden and unexplained deaths (definite, probable, and possible) were recorded among the 1,000 patients implanted and treated with the NCP device. During this period, these patients had accumulated 2,017 patient-years of exposure. Some of these deaths could represent seizure-related deaths in which the seizure was not observed, at night, for example. This number represents an incidence of 5.0 definite, probable, and possible SUDEP deaths per 1,000 patient-years. Although this rate exceeds that expected in a healthy (nonepileptic) population matched for age and sex, it is within the range of estimates for epilepsy patients not receiving vagus nerve stimulation, ranging from 1.3 SUDEP deaths for the general population of patients with epilepsy, to 3.5 (for definite and probable) for a recently studied antiepileptic drug (AED) clinical trial population similar to the NCP System clinical cohort, to 9.3 for patients with partial onset epilepsy.

⚠ **The NCP device is not curative:** Physicians should warn patients that the NCP System is not a cure for epilepsy and that since seizures may occur unexpectedly, patients should consult with a physician before engaging in un-supervised activities, such as driving, swimming, and bathing, and in strenuous sports that could harm them or others.

⚠ **Obstructive Sleep Apnea:** Patients with obstructive sleep apnea (OSA) may have increased apneic events during stimulation. Cyberonics recommends care when treating patients with preexisting OSA. Lowering stimulus frequency or prolonging OFF time may prevent exacerbation of OSA.

PRECAUTIONS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals.

⚠ **Laryngeal irritation** may result from stimulation. **Patients who smoke** may have an increased risk of laryngeal irritation.

⚠ **Dyspnea** may result from stimulation. **Patients with chronic obstructive pulmonary disease** may have an increased risk of dyspnea.

⚠ It is important to follow **recommended implantation procedures and intraoperative product testing** described in this manual. During the intraoperative Lead Test, rare incidents of bradycardia and/or asystole have occurred. As of October 1998, approximately 3,000 patients had been implanted with the NCP System. Four of these patients were reported to have experienced **bradycardia and/or asystole** during the intraoperative Lead Test. All four patients recovered without sequelae. One of the four patients was implanted with the NCP System. There were no postoperative or VNS-treatment-related cardiac adverse events later reported for that patient. No similar events were reported to have occurred during the clinical studies at the time of implantation or during treatment. The safety of this therapy has not been systematically established for patients experiencing bradycardia or asystole during NCP System implantation.

⚠ **Reversal of lead polarity has been associated with an increased chance of bradycardia** in animal studies. It is important to make sure that the Lead connector pins a correctly inserted (white marker to + connection) into the Pulse Generator header.

⚠ It is important to follow **infection control procedures**. Infections related to any implanted device are difficult to treat and may require that the device be explanted. Cyberonics recommends that the patient be given antibiotics preoperatively. The surgeon should ensu that all instruments, including the NCP Tunneling Tool, are sterile prior to the operation.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve** in the neck area inside the carotid sheath.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve below wher the superior and inferior cervical cardiac branches separate from the vagus nerve**.

⚠ **A neck brace** can be used by the patient for the first week to help ensure proper Bipolar Lead stabilization.

Environmental and Medical Therapy Hazards

⚠ Patients should exercise reasonable caution in avoiding devices that generate a **strong electric or magnetic field**. (For examples, see the "Other Environmental Hazards" sectio of the Physician's Manual.) If a Pulse Generator ceases operation while in the presence of electromagnetic interference (EMI), moving away from the source may allow it to return to its normal mode of operation.

⚠ NCP System operation **should always be checked** by performing device diagnostics afte any of the procedures mentioned in the Physician's Manual.

⚠ Because of where the Pulse Generator is implanted in the chest, **patients may need to b specially positioned in mammography equipment for clear imaging**. Otherwise, the device may be seen as a shadow on the mammogram. (Most routine diagnostic procedure such as fluoroscopy and x-radiography, are not expected to affect system operation.)

⚠ **Therapeutic radiation** may damage the Pulse Generator's circuitry, although no testing h been done to date and no definite information on radiation effects is available. Sources of such radiation include therapeutic x-rays, cobalt machines, and linear accelerators. The radiation effect is cumulative, with the total dosage determining the extent of damage. The effects of exposure to such radiation can range from a temporary disturbance to permanen damage, and may not be detectable immediately.

⚠ **External defibrillation** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for external defibrillation.

⚠ **Electrocautery surgery** may damage the Pulse Generator. Please refer to the Physician Manual for complete instructions for electrocautery surgery.

⚠ **Magnetic resonance imaging** (MRI) should not be performed with a magnetic resonance body coil in the transmit mode. The heat induced in the Bipolar Lead by an MRI body scan can cause injury.

Use caution when other MRI systems are used, since adverse events may occur because different magnetic field distributions.

⚠ No scan in which the radiofrequency (RF) is transmitted by the body coil should be done o a patient who has the NCP System. Thus, protocols must not be used which utilize local coils that are RF-receive only, with RF-transmit performed by the body coil. Note that som RF head coils are receive only, and that most other local coils, such as knee and spinal coils, are also RF-receive only. **These coils must not be used in patients with the NCP System.**

⚠ **Therapeutic ultrasound.** Routine therapeutic ultrasound could damage the Pulse Generator and may be inadvertently concentrated by the device, causing harm to the patient.

⚠ **Extracorporeal shockwave lithotripsy** may damage the Pulse Generator. If therapeutic ultrasound therapy is required, avoid positioning the Pulse Generator part of the body in th water bath or in any other position that would expose it to ultrasound therapy. If that positioning cannot be avoided, program the Pulse Generator output to 0 mA for the treatment, and then after therapy, reprogram the Pulse Generator to the original parameters.

Diagnostic ultrasound is not expected to affect the NCP System.

⚠ The Pulse Generator may affect the operation of **other implanted devices,** such as cardi pacemakers and implantable defibrillators. Possible effects include sensing problems and inappropriate Pulse Generator responses. If the Pulse Generator patient requires concurrent implantable pacemaker and/or defibrillator therapy, careful programming of ea system is necessary to optimize the patient's benefit from each device.

ADVERSE EVENTS

Adverse events reported during clinical studies as statistically significant are listed in alphabetical order Ataxia (muscle movements or twitching, generally associated with stimulation); Dyspepsia (indigestion); Dyspnea (difficulty breathing, shortness of breath); Hypesthesia (impaired sense of touch); Increased coughing; Infection; Insomnia (inability to sleep); Laryngismus (throat, larnx spasms); Nausea; Pain; Paresthesia (prickling of the skin); Pharyngitis (inflammation of the pharn throat); Voice alteration (hoarseness),Vomiting.

Other potential adverse events possibly associated with surgery or stimulation include but are limited to the following:

Aspiration (fluid in the lungs); Blood clotting; Choking sensation; Damage to nerves or vasculature the surgical area, including the carotid artery and jugular vein; Device (Generator and/or Lead) migration or extrusion; Dizziness; Dysphagia (difficulty swallowing); Duodenal ulcer, gastric ulcer; Ear pain; Facial flushing; Facial paralysis, paresis; Foreign body reaction to implants, including possible tumor formation; Formation of fibrous tissue, pockets of fluid; Heart rate and rhythm changes; Hiccuping; Incision site pain; Irritability; Laryngeal irritation (sore, painful throat); Left hemidiaphragm paralysis; Left recurrent laryngeal nerve injury; Left vocal cord paralysis; Low-grad fever; Muscle pain; Neck pain; Nerve injury; Painful or irregular stimulation; Skin, tissue reaction; Stomach discomfort; Tinnitus (ringing in the ears); Tooth pain; Unusual scarring at the incision sit Urinary retention; Vagus nerve paralysis; Weight change; Worsening of asthma and bronchitis; Worsening of cardiac abnormalities, including heart rate and rhythm.

⚠ Patients who manipulate the Pulse Generator and Bipolar Lead through the skin may dama or disconnect the Bipolar Lead from the Pulse Generator and/or possibly cause damage to vagus nerve.

---

[1] The information contained in this Executive Summary for Physicians represents partial excerpts of important prescribing information taken from the *NCP Pulse Generator Physician's Manual*. The information is not intended to serve as a substitute for a complete and through understanding of the material presented in all of the Physician Manuals for the NCP System and its component parts nor does this information represent full disclosure of all pertinent information concerning the use of this product, potential safety complications, or efficacy outcomes.

Exceptional Parents and the Exceptional Stress of the Holidays

—**Excerpted and modified from Lisa Groen Braner's *The Mother's Book of Well-Being***

AVAILABLE AT THE EP LIBRARY WWW.EPLIBRARY.COM

How many years did you walk through a shopping mall during the holidays, hurrying past the long line of parents and children waiting to sit on Santa's lap? You might have held your breath as you burrowed through crowds, determined to make it to as many stores as possible. Maybe you saw the lighted snowflakes hanging from the ceilings. Listened to the student choir serenading you with carols full of hope, goodwill and peace…

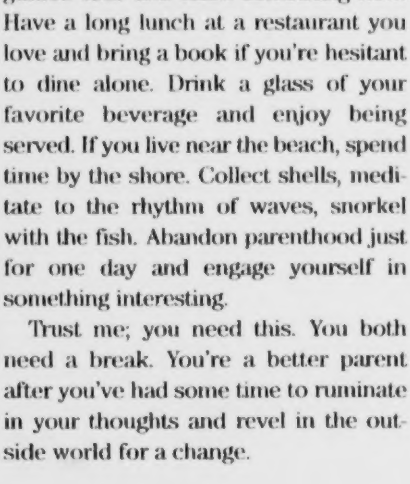
For my son's first Christmas, I stood in Santa's line with many other new mothers and fathers, our babies tucked in arms or strollers. Life-sized red and green candy canes flanked the entrance to Santa's den. Parents peered around winter coats and shopping bags, eagerly trying to catch a peek of the white bearded man dressed in red velvet. The elves and Mrs. Claus worked the crowd, cooing at babies and handing out peppermint sticks and order forms. It's possible that we were the most cheerful adults in the mall, as though we were meeting Santa for the first time. Then suddenly, as if led by the Ghost of Christmas Past, I saw my old self stride past me. She sighed, checked her watch a couple times, and darted into a store and out of my view. She didn't bother looking our way. Her hurried pace and fixed gaze made me realize how much my son had opened my eyes again to life.

What was your first Holiday season as an Exceptional Parent like? Perhaps you found yourself in the Santa line, remembering your own childhood. Holidays are a time to cherish our children and to reflect on the challenges both our children and us must face in this world. Not only is it essential for you to take time to give to your children, don't forget to take time for yourself and your spouse.

The Holiday season is a great time for you to schedule a day off for yourself. I'm referring to the whole day, not two hours in a shopping mall. Imagine what you would do with a whole day off. Take some time to think about it; the ideas will come to you quickly.

Hiking in a state park might fit the bill, staring up at the sky through limbs and leaves. If weather doesn't permit, visit your favorite museum. Pay for a guided tour and learn something new. Have a long lunch at a restaurant you love and bring a book if you're hesitant to dine alone. Drink a glass of your favorite beverage and enjoy being served. If you live near the beach, spend time by the shore. Collect shells, meditate to the rhythm of waves, snorkel with the fish. Abandon parenthood just for one day and engage yourself in something interesting.

Trust me; you need this. You both need a break. You're a better parent after you've had some time to ruminate in your thoughts and revel in the outside world for a change.



For my first whole day away from motherhood, I drove to the city for a morning of art and an afternoon of "high tea." While browsing Picasso's lesser-known drawings, I listened to a string quartet that formed unexpectedly in the museum's lobby. At tea, I nibbled cucumber sandwiches and miniature French pastries. I sipped English Breakfast tea from china and relaxed into an armchair covered in tapestry. My day felt extravagant and cushy. My first holiday from motherhood made a lasting impression; now when the days and weeks overpower my patience and stamina, I make plans for another.

"Having a baby is living in the eternal now. Having a baby means caring intensely about the stage you're going through, while forgetting everything that happened more than a week ago," says mother and writer Alisa Kwitney about the timelessness and novelty of maternal life in her essay "The Eternal Now." Children reawaken our senses, allowing us to share their joy in experiencing a single moment. So many moments call to us if we will only listen. May this holiday season rekindle your awareness of the simple pleasures in life as well as provide you with hope and strength for the coming year. EP

NEVER PAY FULL PRICE AGAIN!!
EP PREFERRED BUYER CLUB OFFER!

EP PREFERRED BUYER CLUB!!

A Charter Membership in the EP Preferred Buyer Club includes the following special benefits:

* A personalized EP Membership Card
* 10% Discount on all books in the EP Library
* 10% Discount on all videos in the EP Library
* 20% Discount on all EP Monographs and Special Reports
* $7.50 Discount on annual subscription to EP Magazine or renewal during term
* One free ticket to the World Congress Exposition on Disabilities
* Gift Certificate for FREE SHIPPING on next order
* Only $24.95 per year

Take advantage of this dynamic offer now!
You can sign up any one of the following ways:
CALL 800-535-1910 or Visit
www.eparent.com & www.eplibrary.com

YES!! I want to join the EP Preferred Buyer Club so that I won't have to pay full price again !

Mail to: Exceptional Parent Dept: Membership P O Box 1807 Englewood Cliffs, NJ 07632-1207
Or Order on-line: www.eplibrary.com/epreferredbuyerclub/ Fax (201-947-9376 Or call 800-535-1910

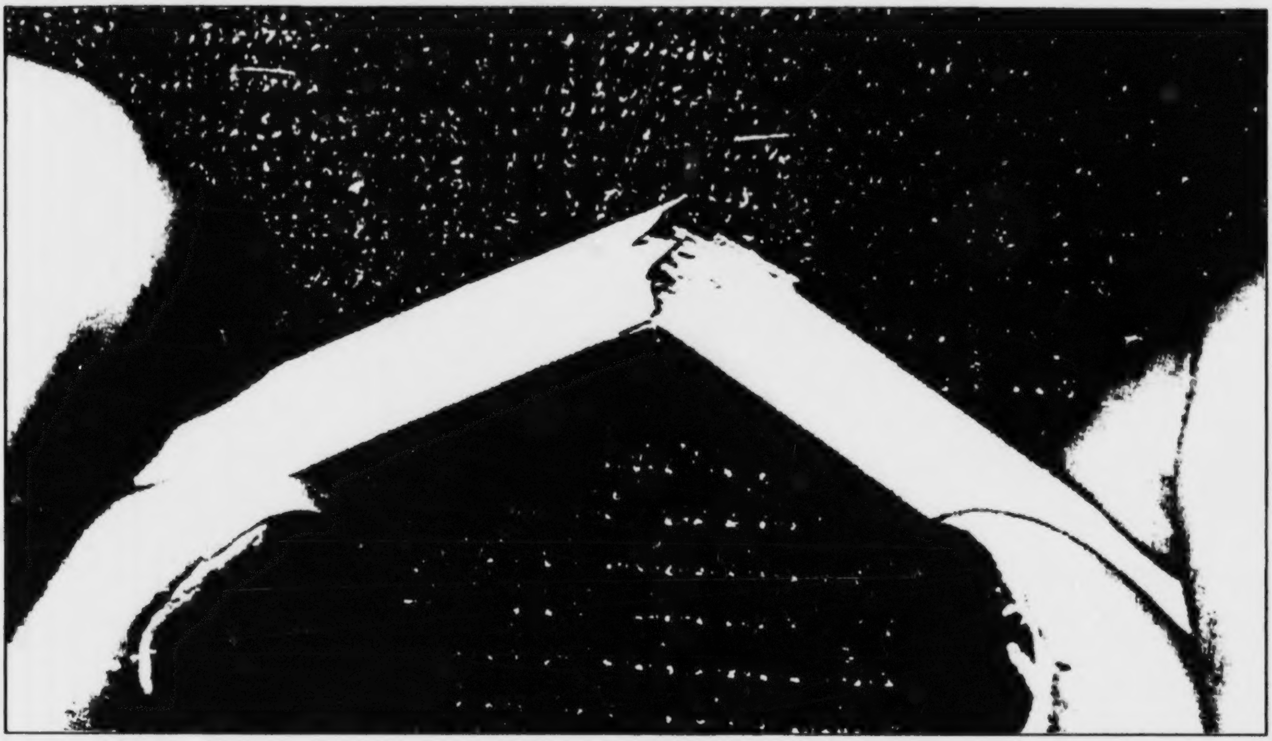
Name: ____________________
Address: ____________________
City: ____________________ **State:** __________ **Zip Code:** __________
Telephone: ____________________ **Email:** ____________________

I have enclosed my check payable to Exceptional Parent or charge to my:

☐ **VISA** ☐ **Mastercard** ☐ **AMEX** ☐ **Discover**

Account Number: _ _ _ _ - _ _ _ _ - _ _ _ _ - _ _ _ _ , **Exp. Date:** ___/___ **Signature:**

Circle #200 or visit www.eparent.com/adinfo



Self-Regulation and STRESS Management

Carolyn G. Cantu, MS, OTR

Imagine stress levels rising as your child experiences a "behavior meltdown" at the supermarket's check-out counter. Imagine the apprehension developing in your classroom as a particular child once again unsettles your class with disruptive behavior. Children with underdeveloped self-regulation repeatedly exhibit unruly behavior. Stress levels often increase in them, their families, teachers and classmates. Teaching the child to regulate his or her own nervous system decreases stress and promotes an overall sense of calm.

Stress experienced by parents, caregivers, therapists and teachers who live or work with an exceptional child is a common phenomenon. If adults feel stressed, think of the tension children feel when their minds and bodies are experiencing ongoing agitation. Recently, an adult interviewed on a television broadcast about ADHD described her childhood as "listening to ten radios being played in my head at the same time." This is a clear example of the internal sensations some children experience throughout each day. Sometimes

continued on page 42

continued from page 41

every calming technique tried is of no avail, causing stress to spiral upward for children and their caregiving adults.

Figures relating specifically to children with self-regulation problems are difficult to obtain. We do know, however, that recent statistics show three to five percent of all school age children are diagnosed with ADHD. Representing only one diagnostic category, that statistic alone presents a snapshot of the impact disruptive behavior has on households and classrooms.

Without self-regulation as a component of overall intervention it is possible for these behaviors to intensify, causing stress to escalate and remain at an elevated level.

Which are those conditions connecting stress to behavior patterns?

Children experiencing ADD, ADHD, Down syndrome, developmental delays, sensory processing dysfunction, learning disabilities, social stress and/or crisis situations share some characteristics. Disruptive behavior, clinging to adults, intrusion into others' space, inappropriately loud voices, difficulty with transitions and occasional tantrums are common behaviors reported by parents and teachers. Without self-regulation as a component of overall intervention it is possible for these behaviors to intensify, causing stress to escalate and remain at an elevated level.

If any of us as parents, teachers or therapists are experiencing this connection with special needs children, we might benefit from a closer look at what is defined as self-regulation and how it reduces stress in those under our care.

Definitions and Approaches

Self-regulation is addressed by a variety of health and educational disciplines. Professionals define and approach stress reduction from their respective frames of reference. For example, pediatricians focus on the physiological effects of stress on the child and family, pediatric occupational therapists from sensory processing and sensory organization models, educational psychologists and researchers from the cognitive component and child psychologists from the emotional/social component.

As defined by Mary Sue Williams, OTR/L and Sherry Shellenberger, OTR/L, "Self regulation is the ability to attain, maintain and change arousal (alertness) appropriately for a task or situation The child's behavior may reflect both the current level of organization of the nervous system and his best attempt to respond adaptively and efficiently to the demands of a situation or task" (http://www.alertprogram.com).

Occupational therapy's sensory integration approach to self-regulation

Children experiencing regulatory problems frequently exhibit sensory defensiveness to external stimuli, demonstrate resistance to calming efforts and demonstrate difficulty with eating and sleeping schedules. Under the guidance of A. Jean Ayres, PhD, OTR, occupational therapists have, since the 1960s, used varied tactile and movement input to desensitize or regulate some of the disorganization that these children were experiencing. Therapists soon noted that follow-through at home and school became an issue. How were therapists able to have sensory input reinforced and followed through at home without putting more of a burden on parents and teachers?

In 1994 and again in 1996, Williams and Shellenberger published a workbook offering therapeutic strategies to develop children's "alert systems," leading toward self-regulation. Alert systems may be thought of as sensitivity to arousal states, both controlled and uncontrolled. Their Alert Program addresses self-calming/self-regulating from this sensory awareness perspective. Building upon neurological development and the body's sensory system as a foundation, Williams and Shellenberger devised a cleverly effective program enabling parents, teachers and children to become aware of individual levels of alertness or arousal states. "Is your engine running high, low or just right?" becomes a standard question children learn to answer. They are then taught to adjust their alert levels to be appropriate to the activity or situation experienced at the moment. Using the central nervous system's seven sensory processes, the program teaches "how to recognize arousal (alert) states as they relate to attention, learning and behavior." The program follows through by offering children a variety of self-regulation strategies and activities they can use independently at home, school or in the community. Self-control increases—stress decreases.

A Cognitive/ Behavioral Approach:

The Early Education Clearinghouse, Boston, MA (http://www. factsinaction.org), notes that: "Self-regulation includes a child's ability to control his or her thoughts, responses and actions. Evidence suggests that the ability to self regulate during the early years of life is related to self-control in later childhood and throughout life. It also appears to contribute to social skills and school success."

This approach takes place at a higher level in the brain than the sensory approach. The child must stop, develop a cognitive awareness of the ineffective behavior, select a learned alternative behavior and follow through. In his book "Development and Self Direction," Professor Rafael Diaz focuses on school preparation. He states, "as a child's self direction/self regulation increases, the adult's direction may gradually be withdrawn, allowing the child to 'take over.'" Dr. Diaz identifies

continued on page 44

Worth the work

Autism doesn't diminish Jack's need to assert his independence, but it does create some obstacles. At Heartspring we provide him with a picture schedule in the home and classroom settings to give each day a predictable structure. It's working remarkably well for everyone involved; Jack gets to enjoy an enhanced sense of self-worth ... we get to see that great smile.

HEARTSPRING℠
SCHOOL
Finding New Ways for Learning
8700 East 29th Street North • Wichita, Kansas 67226
call 1-800-835-1043
www.heartspring.org

Circle #18 or visit www.eparent.com/adinfo

continued from page 43

this concept as "developmentally appropriate practice" and defines self-direction as " the child's ability to plan, guide and monitor his/her own behavior flexibly and from within to change circumstances. By teaching self-direction the adult is teaching autonomy." Dr. Diaz points out the difference between self-direction and self-control. He defines self-direction as the ability to take direction from the adult within the adult's presence; and self-control as the ability to act according to the dictates of the caregivers in the absence of the caregiver.

The concept of gradually reducing structure and instruction as the child gains self control and discipline is appropriately applied to children experiencing behavioral difficulties.

Behavior modification techniques are also in the category of helping children control their responses. Acceptable behavior is repeatedly rewarded at home and school, as parents and teachers carry out a cooperative effort. These rewards occur in close succession, perhaps as frequently as every five to 15 minutes for the first week or two. Intensity of the program continues until the child is conditioned to extend the acceptable behavior for longer and longer periods of time. After four to six weeks there is generally a marked difference in the child's responses to interaction with others, changes in time, place, person or activity and ability to handle conflicting situations. Unacceptable, disruptive behavior is replaced by acceptable, effective behavior. Positive behavior reduces stress.

By developing sensitivity to those disturbing triggers, parents and teachers can divert children from situations that usually escalate.

Equally important is the development of self-regulation on an emotional/social level. A child's appropriate interaction with family, teachers and peers reduces stress for all those involved with the child. Dr. Gabor Maté's book Scattered outlines the difficulties some children experience in responding appropriately to social cues. These are the children who intrude into others' space and have a difficult time understanding why adults and peers avoid them or become upset with them, stress levels increase and confrontation occurs. Social self-regulation techniques need to be taught by parents and teachers so that these social intrusions do not become a constant cause of stress in the family or with peers.

Dr. Maté emphasizes the use of adult modeling. Because adult behavior makes such a lasting impression, children will imitate and eventually adopt the adult's self-regulatory behavior as their own. This strategy, along with acceptance regardless of behavior, builds the child's self-acceptance. Dr. Maté logically concludes that an "increase in self-acceptance decreases the need to demand it from others"—another positive effect of developing self-regulation. When the demand from others decreases, stress decreases (http://www.scatteredminds.com).

Yet another internationally known expert addresses the emotional/social aspect of self regulation and stress. Bruce D. Perry, MD, PhD, writes about stress response systems and self-regulation on the web site www.scholastic.com. He states, "As we mature, our brain requires that we actively participate in regulation....When a child's capacity for self-regulation does not develop normally, he is at risk for problems from tantrums to impulsiveness to difficulty regulating his own sleep and diet."

Dr. Perry reinforces understanding of self-regulation by acknowledging the importance of recognizing a poorly-organized nervous system. He addresses the concept of poor organization from a medical/psychological standpoint: "Many children have difficulty with self-regulation because their stress response systems are poorly organized and hyperactive."

From modeling self-control to seeking professional assistance early, he presents aids on his website (http://teacher.scholastic.com/professional/bruceperry) for parents and teachers to include in their daily routine. These strategies assist parents and teachers to significantly diminish stress.

With the help of pediatric occupational therapists, sensitize the child to his or her own arousal or alert states. Observe what triggers escalation. As Williams and Shellenburger ask, "Is your engine running on low, high or just right?." Incorporate those activities and techniques that the thera-

continued on page 46

Resources

Additude Magazine, ©1998-2002. www.scholastic.com/smartparenting/earlylearner/social/all-selfreg.htm

Cuskelly, Monica M., PhD, Zhang, A., Gilmore, L., "The Importance of Self Regulation with Children with Down's Syndrome." International Journal of Disability Development and Education. Vol. 45, Pg 331-341. University of Queensland, Australia, 1998.

Felstiner, Sarah. "Professor Rafael Diaz, Development of Self-Direction." The Bing Times, The Bing Nursery School, School of Education, Stanford University. © 1992, updated 1997.

"Helping Kids Help Themselves." Facts In Action in the Classroom. Associated Early Care and Education, 95 Berkeley Street, Boston, MA 02116. www.factsinaction.org.

Kranowitz, Carol S. The Out of Sync Child: Recognizing and Coping with Sensory Integration Dysfunction. 1998, Perigee Press, ISBN 0399523863

Maté, Gabor, MD. Scattered. 1999, E. P. Dutton. ISBN 0525944125.

Messina, James J., PhD, Messina, Constance M. "Parents' Tool Box: Tools for Coping with Life's Stressors." Tools for Parents of Children with Special Needs. www.coping.org/coping/book/adhd.htm

Parker, Harvey C., PhD. Listen, Look & Think: A Self-Regulation Program for Children. Audiocassette and booklet. 2001, Specialty Press, ISBN 1886941122. www.ADDwarehouse.com.

Perry, Bruce, MD, PhD. "Self-Regulation, The Third Core Strength." Scholastica Early Childhood Today. 2002-1996. http://www.scholastic.com/professional/bruceperry.

Shellenberger, Sherry, OTR/L and Williams, Mary Sue, OTR/L. "How Does Your Engine Run? A Leader's Guide to Self-Regulation." 1994, 1996, Therapy Works Inc. Albuquerque, NM 87120. ISBN 0964304104. http://www.alertprogram.com.

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel**. Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #34 or visit www.eparent.com/adinfo

Combine two separate methods to defuse the potential explosion: (1) give the child a cracker to munch, providing sensory input in joints and muscles of the face and mouth; and (2) sidestep the tantrum by talking out.

pists suggest into your family routine and household schedule.

Help children manage emotions before provocation leads to aggression. By developing sensitivity to those disturbing triggers, parents and teachers can divert children from situations that usually escalate. Talk out the situation with the child and suggest an alternative in handling the disturbance.

To return to the supermarket: store tantrums usually occur when a child has had too much visual, auditory and tactile stimulation. The overload often occurs right at the check-out counter. Combine two separate methods to defuse the potential explosion: (1) give the child a cracker to munch, providing sensory input in joints and muscles of the face and mouth; and (2) sidestep the tantrum by talking out. "Joey has the box of animal crackers and you want the box; let's all take crackers in our hands and leave the box in the cart." Decreasing the aggressiveness by talking out the immediate situation tends to ward off the tantrum.

Duplicate the structure and repetition experienced in the clinic or special education classroom. This reinforces efforts of therapists and teachers and promotes composure and calm at home. Ask the therapist and teacher for home strategies that reinforce self-calming methods used in the clinic or classroom.

Attend community or university workshops presented by psychologists or special education teachers. Look for those concentrating on behavior modifica-

HDIS

Convenient Home Delivery of Bladder Control Products

Get a FREE bladder control products catalog from the caring professionals at HDIS.

At HDIS, we've been providing discreet home delivery of bladder control products for more than 16 years.

Our friendly, knowledgeable Customer Care Representatives will help you choose which products are right for your child, and answer any of your questions. ***Name brands always in stock—Depend®, Attends®, Reassure®, Tranquility® and more!***

FREE CATALOG!
Call 1-800-2MY-HOME®
(1-800-269-4663)

"If you have any questions, give us a call. We'd be happy to help."
– Mary

Call now to get your FREE 40-page HDIS catalog of bladder control products and over $45 in coupons—all sent to you in a discreet envelope.

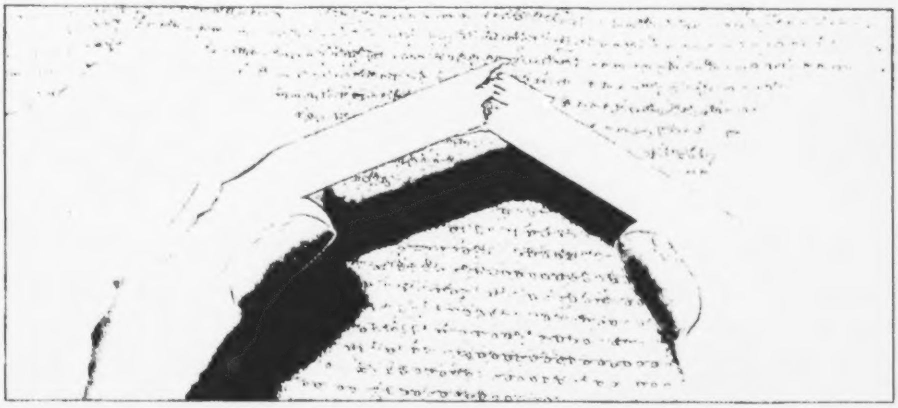
All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

024-135

Circle #37 or visit www.eparent.com/adinfo

1270

tion or self- regulation strategies easily applied at home.

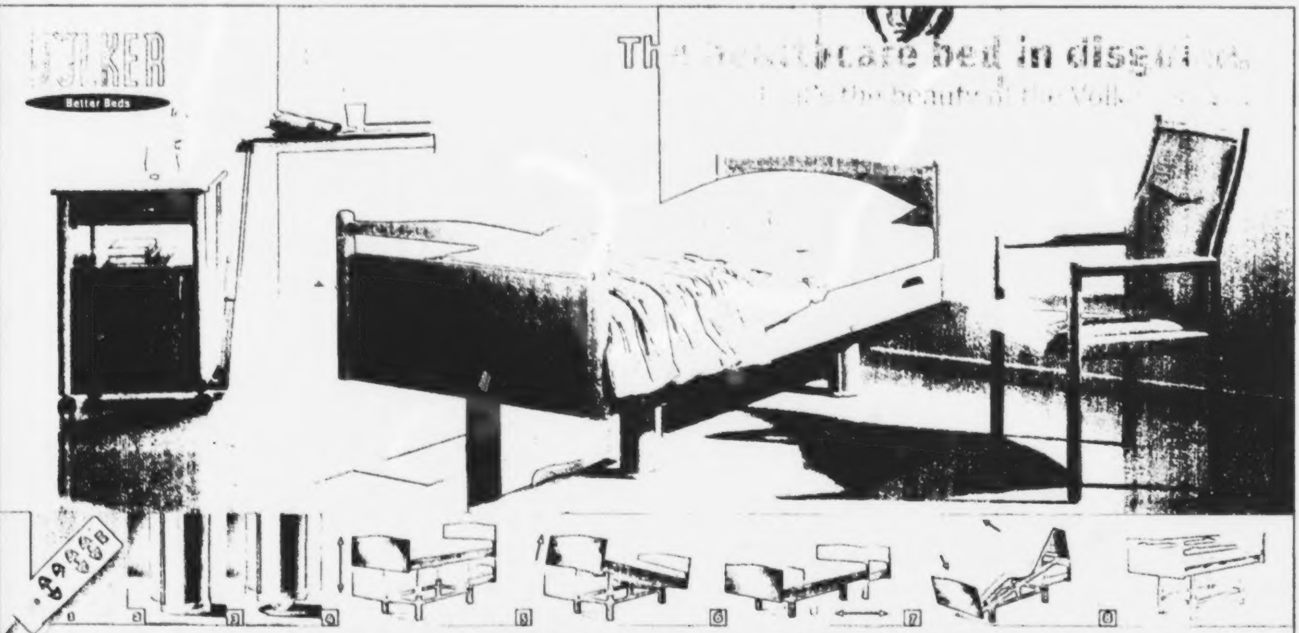


Conclusion

Physicians, pediatric occupational therapists, child psychologists and educational researchers agree that by increasing the child's self-regulatory ability, stress decreases for both child and parent. Added benefits include a rise in the level of the child's self-discipline, self-esteem and self-confidence. Whether the program of choice is based on sensory processing, alert system awareness, cognitive techniques or emotional/social intervention, self-regulation reduces burdensome stress in some exceptional children, their families and teachers. The important thing to remember is that no one program is a panacea for stress management. Integrating the best strategies from varied approaches to self-regulation has the best chance for success with stress release. EP

Carolyn O. Cantu, MS, OTR, is a licensed pediatric occupational therapist and educator who has practiced and taught all over the world for 32 years.

Most recently, she was a pediatric therapist and clinical educator for the Infant Parent Program, Austin, TX.



1. Electric operation via a hand control or nurse console (optional). 2. Absolutely secure braking. 3. Electric push button casters. 4. Stable height adjustment 15 1/2–31 1/2" (13 3/4–27 1/2" optional). 5. Trendelenberg/reverse Trendelenberg (optional). 6. Easy to move on disappearing casters. 7. Tilt-in-space positioning that allows for sitting (cardiac) or reclining chair. 8. Disappearing full lenght side rails.

Hertz SUPPLY

For more information call 1-800-321-4240

Hertz Supply Co., Inc. · 4670 Schantz Rd., Suite A · Allentown, PA 18104 · www.hertzsupply.com

Circle #40 or visit www.eparent.com/adinfo

8 Tips for a Stress Free Holiday Season

Enjoy More by Doing Less

This holiday season demands weeks of preparation—buying gifts, mailing cards, planning parties. Author Christine Klein (The Simpler Family, Robin Lane Press 2001) offers some advice to relieve the stress and regain the spirit of the season when the holidays become too hectic to enjoy.

Plan the celebration that YOU want, not the one the others expect it to be. Ask yourself this question: "If our family could spend the holidays the way WE want, how would it be different?" If it's too late to alter the course for this year's celebration, it's a good time to drop hints about your new plans for next year.

1

Lower your expectations. If you expect perfection, you will surely be disappointed. The kids will be restless at church. At least one toy won't work. One or more of your relatives will be irritating. And your house will not look like Martha Stewart's. Plan on it.

2

Skip the cards. If the holidays are too hectic to send cards, send Happy New Year or Valentine or St. Patrick's Day greetings instead. You'll have more time to prepare them and your recipients will have more time to appreciate them during the less-hectic time of year.

3

Keep the decorations simple. Hang a wreath on the door and position a spotlight nearby. Or place an electric candle in every window. Sometimes the simplest decorations can be the most attractive.

4

Let the children do the decorating. Somehow a tree that is slightly off-kilter with ornaments hung only as high as a child's hand can reach is more perfect than a tree decorated by adults.

5

Ask your guests to help. A potluck holiday meal is easier on the hostess (who must also clean the house), and gives everyone an opportunity to show off their best dish.

6

Begin your own family rituals that add quiet meaning to the holiday. Sprinkle birdseed outdoors just before bed so the birds wake-up to a happy surprise. Deliver homemade cookies to a homeless shelter. Make time for someone who's lonely.

7

Simplify gift-giving. Suggest to family members that gifts be given only to children. Or institute an exchange of names so you'll buy for only one adult or child instead of everyone.

8

Avoid the mall and give gifts from the heart. A written note of love is a greater treasure than a store-bought gift. "Five reasons why I think you're a great _____" is an ideal gift from student to teacher, child to parent or grandparent, or anyone special in your life.

Buy simple gifts: A favorite book, tickets to the zoo, a monthly car wash, dinner during the slower winter months. EP

Christine Klein is a graduate of Bowling Green University with a Bachelor of Science in Journalism. She left a successful marketing career to pursue her dream of living her life on her own terms, by working less and spending more time with her husband and two children. Her book, The Simpler Family, is the product of the strategy she created to accomplish that. Now a marketing consultant and freelance writer with plenty of time for her family and herself, she lives in Cincinnati, Ohio.

Charles C Thomas
PUBLISHER • LTD.

2600 South First Street
Springfield, IL 62704

Forthcoming releases from Charles C Thomas, Publisher!

PSYCHOLOGICAL AND EDUCATIONAL TEST SCORES
What Are They?

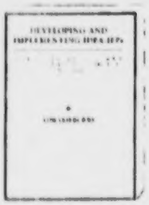
Published 2002, 196 pages
Marty Sapp
hard ISBN 0-398-07258-2
paper ISBN 0-398-07259-0

PEDIATRIC MUSIC THERAPY

To be published 2002, 344 pages
Wanda B. Lathom-Radocy
hard ISBN 0-398-07301-5
paper ISBN 0-398-07302-3

ENDING DISCRIMINATION IN SPECIAL EDUCATION
(2nd Ed.)

To be published 2002, 150 pages
Herbert Grossman
paper, ISBN 0-398-07304-X

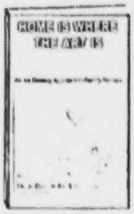


DEVELOPING AND IMPLEMENTING IDEA-IEPs
An Individualized Education Program (IEP) Handbook for Meeting Individuals with Disabilities Education Act (IDEA) Requirements

Published 2001, 274 pages
Edward Burns
$59.95, hard ISBN 0-398-07122-5
$40.95, paper ISBN 0-398-07123-3 (displayed)

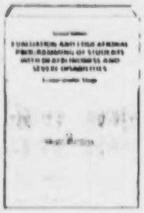
HOME IS WHERE THE ART IS
An Art Therapy Approach to Family Therapy

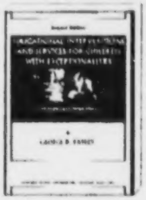
Published 2001, 224 pages
Doris Banowsky Arrington
$61.95, hard ISBN 0-398-07160-8
$42.95, paper ISBN 0-398-07161-6



EVALUATION AND EDUCATIONAL PROGRAMMING OF STUDENTS WITH DEAFBLINDNESS AND SEVERE DISABILITIES
Sensorimotor Stage (2nd Ed.)

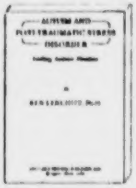
Published 2001, 294 pages
Carroll J. Jones
$45.95 paper ISBN 0-398-07216-7 (displayed)





EDUCATIONAL INTERVENTIONS AND SERVICES FOR CHILDREN WITH EXCEPTIONALITIES
Strategies and Perspectives (2nd Ed.)

Published 2001, 304 pages
George R. Taylor
$66.95, cloth ISBN 0-398-07112-8
$44.95, paper ISBN 0-398-07113-6 (displayed)

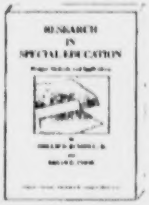


AUTISM AND POST-TRAUMATIC STRESS DISORDER
Ending Autistic Fixation

Published 2000, 136 pages
Kenneth Lenchitz
$36.95, cloth ISBN 0-398-07096-2
$19.95, paper (displayed) 0-398-07097-0

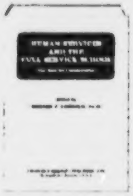
RESEARCH IN SPECIAL EDUCATION
Designs, Methods, and Applications

Published 2001, 268 pages
Phillip D. Rumrill, Jr., & Bryan G. Cook
$56.95, cloth ISBN 0-398-07172-1
$38.95, paper ISBN 0-398-07173-X (displayed)



HUMAN SERVICES AND THE FULL SERVICE SCHOOL
The Need for Collaboration

Published 2000, 128 pages
Robert F. Kronick
$18.95, paper ISBN 0-398-07063-6



Programmed Therapy FOR STUTTERING in Children and Adults (2nd Ed.)

Published 2000, 360 pages
Bruce P. Ryan
$79.95, hard ISBN 0-398-07106-3
$54.95, paper ISBN 0-398-07107-1

Contact us to order books or a free catalog with over 811 titles

Call 1-800-258-8980 or 1-217-789-8980 or Fax 1-217-789-9130
Complete catalog available at www.ccthomas.com • books@ccthomas.com

Books sent on approval • Shipping charges: $6.95 U.S. / Outside U.S., actual shipping fees will be charged
Prices subject to change without notice

Circle #22 or visit www.eparent.com/adinfo

LOW-COST & FREE HEALTH CARE COVERAGE
MANY WORKING FAMILIES ARE NOW ELIGIBLE!

You work hard to take care of your kids...

Now there's help.

YOUR CHILD CAN BE COVERED FOR:

- DOCTOR VISITS
- HOSPITALIZATION
- PRESCRIPTIONS
- OTHER BENEFITS

Make sure your kids are covered to get the care they need to stay well...and protect your family budget.

Ask about the low-cost or free health care coverage programs in your state.

CALL 1(877) KIDS-NOW TOLL-FREE

The Story OF A Pediatrician/ Parent

By Jo Feingold, MD

This article is the first of a two part story that chronicles a mother's—and a pediatricians—journey from early treatment and initial opposition to HBOT and then to her "conversion" to the therapy.

Tonight for the first time in years I sat and ate by myself. I don't mean I ate alone; I mean it was the first time in several years I didn't have to feed someone. My name is Jo Feingold and I am a physician—a pediatrician. My fervent hope is that by sharing my experiences as the mother of five children, including a set of triplets, it will help dispel the myth that all doctors are insensitive to parents of special-needs children and reinforce the need for more openness on the part of my profession—medicine—to alternative therapies for people with disabilities.

David Feingold and his daughter, Elisa

A Story About Family:

The "someone" I did not have to feed is my daughter Elisa. I have been blessed with five children. My seven-year-old is Daniela; Elisa is six and the triplets, Jonathan, Michael, and Jackie, are five. Every night we sit around the dinner table and discuss who will sit next to whom. Each one of my children "calls " for me to sit next to him or her. This could be an easy choice every night because, in theory, I could sit between any two of them. However, this is not possible, because Elisa has cerebral palsy. She needs me to sit next to her every night. She is more comfortable with me. My other children seem to understand and so they take turns at sitting next to me.

Tonight Daniela intervened on her brothers' behalf. Both cried to sit next to me. I attempted to cajole one of them to sit across from me, but it was useless. Daniela then told me to sit in between the boys and she would feed Elisa. This may seem like an insignificant gesture on the part of a small child, but it really is a sign of incredible maturity, sensitivity and caring. As a mother and health care professional, I am faced with the reality that I have a daughter with special needs who may never really achieve independence. I am also faced with the reality that neither I nor my husband will be able to take care of her forever. I see how the other children react. Their willingness to step up to the plate in taking care of their sister moves me. Tonight it was Danny's turn. Two days ago, as I was carrying Elisa to the bathroom, Jonathan told me that one day soon he would do that "because he's getting bigger." Their compassion and sensitivity fill me with a sense of emotion I have difficulty expressing in words. It is in precious moments such as these, when the reality of the whole situation sets in, that makes my heart fill with pride and love.

Parent Thoughts and Dreams

I became a mother and fully accepted the responsibility of my five miracles. Like any other mother, I have an incredible desire to protect, nurture, love and teach my children. The hardest part of being a parent is the knowledge that I will one day have to let go, and the nagging fear that that day may never arrive for one of my children. I have sat and pondered what would make me happy as a mother; what do I really want for these children? Do I want them to be physicians,

continued on page 52

continued from page 51

lawyers, scientists, mothers, fathers? My answer is always the same: I want them to be happy. I want them to be good people. I want them to understand and appreciate the precious gift of life and that all people are not created equal; so we are, all of us, responsible to help those who cannot help themselves. I want them to grow up to be people who will find it in their hearts to reach out and feed someone who is hungry, and to have the dignity to carry themselves with poise and strength. I want them to be able to be awed by a sunset, to understand that faith is important, to take strength in the knowledge that they always have each other. I would like each of them to be independent. All five of my children have the capacity of achieving their goals, including Elisa.

Elisa

Writing about Elisa is very painful. I cry almost every time I tell her story and I relive that story every day. It seems like her birth was light years away, yet at times it feels like it was only yesterday. June 13, 1996 was a day which changed my life. This was the day of the anniversary of my father's death. Thirty-five years had passed but the anniversary of his death is still a gloomy day. My mother was staying with me because I had some complications arising from my pregnancy. I was 31 weeks pregnant. I needed someone to take care of my toddler. I wanted to take my mother to church but for some reason she didn't want to leave. She told me she felt she had to be with me and she would pray for my father at home.

In the early afternoon I suddenly began to have vaginal bleeding. Although my doctor was far away, I called him. I remained very calm. I took my pulse and called 911. I told EMS that I was a physician, gave them my vital signs and remained calm. The bleeding continued while I stayed on the phone with EMS. I repeated my pulse. I was still calm. I had two large-bore IV's placed. I was still calm. I was taken to the nearest hospital by ambulance. My mother followed in the police car with Daniela. I remember the delivery room. All the doctors reassured me, but I was feeling weaker by the minute. As they closed the door I looked back to see my mother's face. She was in a panic. She had lost my father on this very day. Was she about to lose a daughter, and possibly a grandchild? Fear—the fear that strikes to the core—began to set in. I felt weaker. My mental status was changing. I remember saying "you're losing me." There were shouts: "give fluids," "call neonatology," "get that baby out." I cried to my father to help me.

The News

Elisa was born. She weighed four pounds, 11 ounces. I thought how lucky I was because she wasn't really tiny. The next three weeks were joyful ones. Elisa made progress. Although I was weak, I found myself in the car every day. We taped her, we took lots of pictures, we fed her and bathed her. I was getting stronger. Finally she was big enough for us to bring her home. They just had to do some routine tests among them a repeat head ultrasound and she would be home. The morning I was supposed to pick her up I got a call from her neonatologist. His words were like a knife in my heart and my world came to a crashing halt. He told me that my daughter had PVL (periventricular leukomalacia). He asked me if I knew what that was. I remember asking him "are you for real?" I reminded him that I was a physician—a pediatrician. He then told me that my daughter could have learning disabilities or muscular problems but "not to worry because probably she would be normal." I could pick her up whenever I wanted.

I knew better. I collapsed. It felt as if life stopped. Things started moving as if in slow motion. I remember what I was wearing, the room I was in, the color of my nails, the tears streaming down my face. I asked for a repeat test, and the result was the same. I asked for a neurology consult. The neurologist came in and talked to the nurses for at least 30 minutes before he addressed me and my husband while, crying, I held my daughter in my arms. The news began to set in.

A Physician's Perspective—How Much I Didn't Know

I took Elisa out of that hospital and got another head ultrasound at New York University Medical Center (NYU). I trained there. I knew all the doctors there. I trusted them. They confirmed the diagnosis and I fell apart—again. I walked the halls of NYU where years before I had roamed as a resident in training. I knew everyone there. I wanted to cry and shout but needed a private place. I wanted to bury myself in the earth, just me and my daughter. I wanted to tell everyone and no one. I was hurting and wanted others to know that; at the same time I wanted to run away. I looked for the head nurse, whom I knew well. I thought maybe I could use her office to collapse. I asked someone to page her. When she finally came, she didn't recognize me. She told me that she had received a call from one of her nurses, who told her there was a distraught woman looking for her. I must have looked horrible; I knew and worked with all those nurses, but not one of them recognized me.

Elisa was three months old when I found out I was carrying triplets. I cried myself to sleep almost every night because I would not see her make any progress. I was terrified at the possibility that the triplets I was carrying would have the same condition. I was advised to do a selective reduction but could not bring myself to do it. We worried a lot, we cried a lot and prayed as we never prayed before. I was on complete bed rest for nine weeks in the hospital. I counted the weeks, the days, the hours. We went through the fear of pre-term labor almost every day. Finally the triplets were born and, by the grace of God, they were fine. Elisa now had an expanded set of siblings and I had my work cut out for me.

Therapies: First Do No Harm.
Treat Until Treatments Do Not Help

Elisa had aggressive therapy from the time she stopped being "borderline normal" at six months, but she didn't make much progress. Her therapists were wonderful. They loved her and were very good with us. I assumed that I was doing all the right things: physical therapy and occupational therapy, speech therapy, early intervention, hydrotherapy, etc. She still was not making any progress.

A distant relative called my house. He told my mother that he had had a stroke and that he got better with hyperbaric oxygen treatments. He saw some children there like my little girl and they were getting better. I was urged to try it. I thought to myself, "How absurd is this? I am a trained physician and I am getting medical advice from a construction worker." I was the physician, the one with all the knowledge; yet this construction worker was telling me about a therapy my colleagues scoffed at, as there simply was not any valid scientific basis for the treatment's use in people with CP. I thought he was crazy. He insisted so many times that I finally called a pediatric neurologist, who confirmed that hyperbaric oxygen therapy was some form of quackery. ■

... TO BE CONTINUED

In the December issue, Dr. Fiengold talks about Elisa's experience with HBOT and outlines why she herself is now an ardent proponent of HBOT.

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

Toys to Enhance Development in Brain Injured Children
by Richard A. Neubauer, M.D., Medical Director

Hyperbaric oxygen is capable of arousing dormant, idling brain cells that have suffered some form of damage, which is characteristic of all CP and brain injured children. The extent of this damage may be seen by functional brain imaging, and the results of any type of therapy, especially hyperbaric oxygenation, may be gauged by improvement in blood flow and metabolism as shown on repeat scans.

As new cells develop in little ones, or as dormant idling cells begin to fire electrically in older children, they need a sense of direction. To provide this, we recommend PT, OT, speech therapy, and at times acupuncture and appropriate counseling.

However, the role of educational, age-appropriate toys must not be overlooked. Toys should be chosen that will encourage developmental progress in the child. Building blocks, shape sorters and color matching games are among the various playthings that promote important fine motor and sensory skills. As children get older, certainly computers play a major role. Stereo players with motivational music tapes such as those from the Monroe Institute in Virginia* will also enhance development. Thus, when the parents of children with special needs look for toys, they should look for educational playthings that can be motivational aids in learning; entertaining items that will also play a beneficial role in their child's development.

Announcing...
The 3rd International Symposium on Hyperbaric Oxygen in Cerebral Palsy and the Brain Injured Child
Richard A. Neubauer, M.D., Symposium Director
July 16-19, 2003
Fort Lauderdale, Florida
For information:
(800) 552-0255
symposium@oceanhbo.com
www.oceanhbo.com

* *For additional information, visit the Monroe Institute's web site at www.monroeinstitute.org.*

(800) 552-0255
Call for free video & information

For more information, visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

EP neither endorses nor denies the effectiveness of hyperbaric oxygen therapy. For Editor-in-Chief statement see the Contents page.

Circle #52 or visit www.eparent.com/adinfo

Announcing A Special Offer From EP Press

Patient Persistence

Adele M. Gill

Patient Persistence

ON SALE NOW! This book celebrates the ability of people to overcome obstacles to achieve their goals. The author, Adele Gill, is a certified disability analyst, a Fellow of the American Board of Disability Analysts, and an advocate of inspirational and motivational self-help. Ms. Gill has divided the book into two sections, Hope and Courage. Both contain selections that deal with turning points in people's lives, times when they found strength, hope, and the courage to persevere in the face of adversity. This book offers help and hope to those who feel that their lives are out of control or that things have gotten so bad that there will never be a way to make them better. Through examples from the lives of real people, this volume demonstrates that there is always a way.

Code # EP8004GN ~~Price $19.95~~ **Sale $15.95**

No Apologies for Ritalin

Vidya Bhushan Gupta, MD

NO APOLOGIES FOR RITALIN

ORDER NOW & SAVE! This book takes an in-depth look at attention deficit disorder/attention deficit hyperactivity disorder (ADD/ ADHD). Vidya Bhushan Gupta, MD, MPH, a Board-certified pediatrician and a Fellow of the American Academy of Pediatrics, is Director of Developmental-Behavior Pediatrics at Metropolitan Hospital Center, New York City. In his book, Dr. Gupta eloquently educates parents of children with ADD/ADHD about the disorder and available treatments, so that they can make informed choices for the care of their children. The first portion of the book describes what is medically known about ADD/ADHD, including causes and diagnostic methods; the second part outlines available treatment options, including Ritalin and other drugs, dietary changes, herbal therapy, and behavior modification. Dr. Gupta's purpose is to help parents of children with ADD/ADHD to stop blaming themselves for their child's disorder and to investigate and use appropriate therapies, including Ritalin and other medications when indicated, without guilt.

Code # EP8012AD ~~Price $19.95~~ **Sale $16.95**

These books are published by EP Press, the book publishing division of Exceptional Parent magazine, the country's oldest and most widely read publication for families of children and adults with disabilities and special health care needs and the physicians, allied health care professionals and special education teachers involved in their care and development. **For a limited time these books can be ordered at this special price by calling EP Library at 800-535-1910, or through their web site at www.eplibrary.com. Use coupon code: EP06015P**

NEVER GIVE UP THE SEARCH TO FIND THE RIGHT PLACE...

"I was advised to settle for something less, but kept searching. When I visited Crotched Mountain there was a tangible difference in attitude– a professionalism, respect, and "can-do" attitude that set them apart. Standards are high and the approach genuine–they really care! I am very happy with Crotched Mountain and most importantly, so is my son Jared. He has grown enormously in many ways and is becoming the young man that I always thought he could become. It's a family's dream, come true!" *—Kathy Berns*

Crotched Mountain School

- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital

- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@crotchedmountain.org

CROTCHED MOUNTAIN

OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #27 or visit www.eparent.com/adinfo

CONTINUING PROGRESS IN The Diagnosis of Autism

By Eric London, M.D.

This month's Autism Spotlight centers on the diagnosis of autism. This first article explores the overall landscape in diagnosis, principally as it involves patients at the far ends of the spectrum, i.e. acute or very mild. The following article examines the great strides made in the diagnosis of autism in the very young. In coming months, this 14-part series will attempt to explore all areas of autism including alternative approaches. Reader comments and discussion are encouraged at epedit@aol.com.

Parents of children with autism know what autism is. We recognize the signs and symptoms, and most of us can instantly spot another autistic child on the playground or at the supermarket.

But it was not long ago that autism was a difficult and often-missed diagnosis.

Autism is considered a spectrum disorder because symptoms and severity vary from individual to individual. Autism is different in each person with the disorder - no two cases are the same.

It remains a challenging diagnosis at the far ends of the spectrum, when a child is so affected by autism that he or she looks "merely" retarded, or when he or she is so high-functioning that, to many, the child appears "ADD" or "OCD" or "merely" eccentric, not autistic. Today many of these children continue to be misdiagnosed.

But for the wide range of children in the middle of the spectrum, the years of diagnostic

continued on page 56

This article was supported by an educational grant from Janssen Pharmaceutica, L.P.

1279

continued from page 55

research has paid off. The diagnosis of autism has now been standardized, and both the clinical and research criteria are quite reliable. "Reliable," in this sense, means that, using the same criteria, anyone with training will make the same diagnosis for the same child.

Symptoms

According to the Diagnostic and Statistical Manual (DSM-IV), issued by the American Psychiatric Association, the general symptoms for autistic disorder include:

- A total of six or more impairments in social interaction; communication; and restrictive or repetitive and stereotypical patterns of behavior, interests and activities.

- Delays or abnormal functioning in social interaction; language as a means for communication; or symbolic or imaginative play, with onset before age three.

- Symptoms that cannot be described as Rett Syndrome or Childhood Disintegrative Disorder.

WARNING SIGNS:
Most specialists agree that a child should be evaluated for autism immediately if he or she has:

- Not babbled or cooed by one year
- Not gestured, pointed or waved by one year
- Not spoken a single word by 16 months
- Not spoken a two-word phrase (on his or her own) by two years
- Experiences any loss of any language skills at any age.

OTHER CONCERNS:
Parents should talk to their healthcare provider about an autism evaluation if they notice their child:

- Does not respond to his or her name
- Cannot tell or describe what he or she wants
- Experience any language delays
- Does not follow directions at all
- Appears at times to have a hearing impairment
- Does not know how to play with toys
- Has poor eye contact
- Appears to be in his or her own world
- Does not smile socially
- Has odd movement patterns
- Has unusual attachment to toys or other objects
- Regularly lines up toys or other items

NATIONAL ALLIANCE
FOR AUTISM RESEARCH

Over the past few years, the National Alliance for Autism Research (NAAR) has made significant investments in a collaborative study designed to identify early signs of autism and whether early interventions can improve the quality of life for children with autism and their families.

Diagnostic consistency is critical because clinicians make autism diagnoses on the basis of symptoms, not causes. There is no blood test or diagnostic scan available for autism; the disorder can only be identified on the basis of observable signs and symptoms.

For autism, as for all of the psychiatric illnesses, these signs and symptoms are listed in a manual called DSM-IV (Diagnostic and Statistical Manual of Mental Disorders IV - see sidebar). If the child has the requisite number of symptoms, the diagnosis of "autism" (or, alternatively, "pervasive developmental disorder not otherwise specified") can be made. This approach is known as a "phenomenological diagnosis" because it is based upon the outward phenomenon that accompany the disorder.

In contrast, many more strictly "medical" diseases can be given an "etiologic diagnosis," meaning that the diagnosis is based on the causes of the illnesses instead of its symptoms.

Take strep throat. The symptoms of strep throat are the patient's report that his throat hurts, and, upon examination, a physician finds inflammation. But a number of different causes can produce an inflamed throat, and the diagnosis of strep is made only when the physician can document that a certain kind of organism-streptococcal baccilli-is present.

Once the bacteria is found, the physician prescribes an antibiotic; if the inflammation is due to a virus, antibiotics will not be effective. Treatment is based on cause, not symptom.

Obviously an etiologic diagnosis is superior to a phenomenologic one. Unfortunately, brain disorders have proved to be so complex that their causes, or etiologies, are still unknown.

So for now we have only a descriptive understanding of what an individual with autism is like: we can "name" the disorder, and describe its symptoms.

The causes of autism remain unknown and there exists no specific medical treatments or cures for autism.

continued on page 58

The High-Low Chair
The Updown Chair

The LadyBug Corner Chair
The Convert-Able Table

Seating and
Positioning
Products
for Children

R.E.A.L. DESIGN
Rehab and Educational Aids for Living
Phone : 1-800-696-7041
Fax : 1-315-429-3071

Circle #53 or visit www.eparent.com/adinfo

The Autism Tissue Program encourages families nationwide to enroll as organ donors so the brain tissue of individuals with autism and related family members can be used for research.

continued from page 57

Children with an autism spectrum disorder usually begin to show clear, identifiable symptoms by the age of 18 months. Many parents and experts can usually detect symptoms before this time, however a formal diagnosis is typically made when the child exhibits a noticeable delay in developing language skills - normally between the ages of two and three.

Over the past few years, the National Alliance for Autism Research (NAAR) has made significant investments in a collaborative study designed to identify early signs of autism and whether early intervention can improve the quality of life for children with autism and their families. Researchers involved in the multi-site project, known as the Baby Sibs Study, are examining the infant siblings of children with autism to develop better diagnostic methods and, eventually, more targeted interventions for younger children.

But aside from common signs and symptoms, what do we know about autism in a more profound sense?

- What is the cause or causes of what we now call autism?

VISION
By VIEWPOINT MOBILITY

The VISION Advantage:
- Rear entry design doesn't limit you--park and go anywhere
- Not a bulky full-size van-- VISION can fit in a small garage
- Everybody can ride-- seats up to 7 passengers or 2 wheelchairs
- Conversions available on Chrysler and Ford minivans

Let VISION take you on the road to opportunities.

For a **Free Video** or a
personal demonstration of the **VISION** call
Toll Free 1-877-368-6022

Circle #61 or visit www.eparent.com/adinfo

Loneliness shouldn't be a side effect of your child's disability.

At Cotting School, boys and girls of all ages and abilities receive countless opportunities to make friends . . . in the classroom, on a field trip, during basketball practice or in physical therapy. As self-esteem increases with each new friendship, talent and personality shine.

OPENINGS FOR YOUNG PEOPLE FOR 2002 – 2003
NEW POSTGRADUATE RESIDENTIAL PROGRAM NOW OPEN

Cotting School—
where your child belongs.
For information or a tour, please call
Janine Brown-Smith at (781) 862-7323.
www.cotting.org www.cottinghopehouse.org

Cotting
SCHOOL

Cotting School is a 766-approved day school in Lexington, MA for children and youth ages 3-22 with physical, communication, and other challenges to learning.

Circle #24 or visit www.eparent.com/adinfo

- When does it start?
- What has gone wrong or is going wrong presently?
- What parts of the body are affected? How does it progress?
- What will the outcome be?

All of these questions need answers. There are many areas of research currently underway to tackle these issues-including genetics, brain scanning, biochemistry, etc.-but probably at this point it is fair to say that none of these are more important than the direct evidence obtained from studying the actual brain tissue from affected individuals.

In recognition of this, NAAR, in collaboration with the M.I.N.D. Institute at the University of California at Davis and the Autism Society of America established in 1998 the Autism Tissue Program, which is an ambitious effort to increase the availability of urgently needed brain tissue for autism research. The Autism Tissue Program encourages families nationwide to enroll as organ donors so the brain tissue of individuals with autism and related family members can be used for research. This gift of tissue brings a tremendous acceleration in the progress of autism research.

Also, the ability to study brain tissue is vitally important to the development of effective treatments. Until research determines the "targets" for potential medications (in most cases the target will be a specific receptor on the surface of a brain cell), it will be impossible to undertake "rational drug development" (meaning drug development directed at a specific, known problem in the brain) for the autism spectrum disorders.

For more information on the Autism Tissue Program or how you can help support autism research, please call (888) 777-NAAR or visit www.naar.org EP

The Autism Tissue Program encourages families nationwide to enroll as organ donors so the brain tissue of individuals with autism and related family members can be used for research.

Eric London, M.D., is co-founder of the National Alliance for Autism Research and the parent of a son with autism.

Established in 1994, the National Alliance for Autism Research (NAAR) is the first private organization in the country dedicated to funding and accelerating biomedical research for autism spectrum disorders. The organization was established by parents of children with autism concerned about the limited amount of funding for autism research. To date, NAAR has committed more than $10 million in grants for biomedical research projects worldwide that seek to find the causes, prevention, effective treatments and, ultimately, cure for autism spectrum disorders. Walk F.A.R. for NAAR is the organization's signature fundraising and autism awareness event, which is held annually in numerous communities across the United States. Additionally, NAAR was instrumental in establishing the Autism Tissue Program, the first parent-led brain tissue donation program dedicated to autism research.

Five Early Signs of Autism

Connie Kasari, Ph.D., and Connie Wong, M.A.UCLA

Timmy was the perfect baby. Quiet and complacent, at 10 months he could play by himself for hours, allowing me to read the paper or do the housework. Unlike our friends' children, Timmy was so much less demanding of our attention. We just assumed he was very bright and independent. We began to worry, however, when his older sister celebrated her 4th birthday, and Timmy was only a year old. With all the friends and relatives around, he suddenly seemed withdrawn, preferring to crouch in a corner by himself, and at times crying as if there was too much commotion for him. Over the next several months, we began to notice other signs that concerned us. Timmy seemed not to notice our comings and goings as much, and by 18 months, still had not spoken a word. We talked to our pediatrician, but were told that he was likely just a little slow to talk-boys often are, and he has a big sister who likes to do things for him. When Timmy still was not talking at 2, we began to look for other help....

Although autism is usually diagnosed when the child is 3 to 4 years old, parents like the mother above often sense that something is wrong much earlier. On average, parents start to worry about their child's development by 18 months of age and voice some of their concerns to a doctor or another professional by age 2.

> **Using tapes and parent memories, researchers have developed the ability to spot signs of autism in very young children.**

But physicians and professionals are hesitant to diagnose autism at very early ages. They know that the early development of children varies, and are often uncertain if a behavior will persist into being considered atypical, or if behaviors that should be present will continue to be absent. If the child is labeled with a problem too early, parents may reduce expectations for the child and restrict the child's access to typical experiences and opportunities. Thus, professionals may take on a "wait and see" stance that delays diagnosis, and ultimately the commencement of intervention services.

Although such concerns are valid, the benefits of early diagnosis vastly outweigh the risks. These benefits include the relief parents may feel in having their concerns validated, and in their ability to address the problem as early as possible. As many studies have now shown, early intervention is critical for the best outcome in children with autism, and many believe the earlier the better. Only with a diagnosis can parents begin to obtain necessary intervention services for their child.

Given the potential benefits of early diagnosis, is it possible to reliably diagnose autism before age 2? The answer is yes. A number of researchers have now studied the early development of children with autism-a not so easy task given that the average age of diagnosis in the United States is 3 to 4 years of age.

Early development of children with autism has been studied by:

- screening large numbers of children for autism-specific behaviors during well-baby checks at 18 months of age;
- asking parents of children with autism to remember back to whether their child showed certain behaviors at certain developmental ages;
- and having parents bring in home videos of children diagnosed with autism when these children had their first or second birthday parties (which parents often videotape).

From these studies, five distinct areas of development are flagged for consideration. All parents should consider these "Big Five" if they suspect that their child may have autism.

1) Does the baby respond to his or her name when called by the caregiver? Within the first few months of life, babies respond to their own name by orienting toward the person who called them. Typical babies are very responsive to the voices of familiar people, and often respond with smiles and looks.

This article was supported by an educational grant from Janssen Pharmaceutica, L.P.

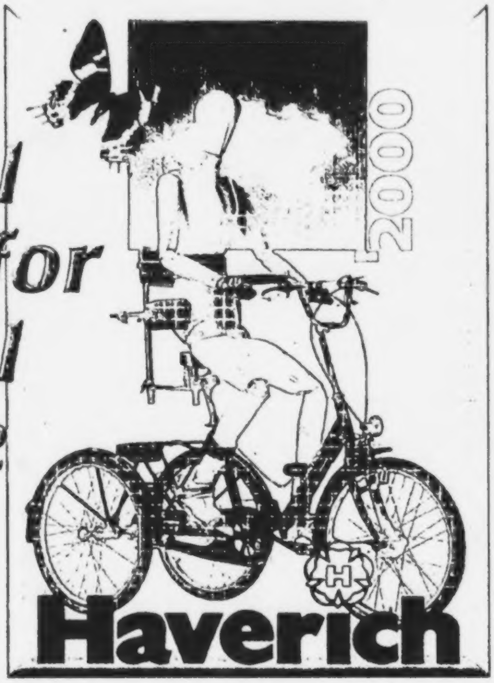
In contrast, infants later diagnosed with autism often fail to respond to their own name. That is, when called by name, they tend to turn and look at the person only about 20% of the time as found in the videotaped one-year-old birthday parties of children with autism. They also are often selectively responsive to sounds. They may ignore some sounds and respond to others that are of the same loudness. Thus, they may fail to respond to their parent calling their name, but immediately respond to the television being turned on. It is not unusual for parents to suspect their child has a hearing loss.

2) Does the young child engage in "joint attention"? Near the end of the first year of life, most infants begin to join with their caregivers in looking at the same object or event. To aid in this process of "joint attention", typical infants begin to shift their gaze from toys to people, follow other's points, monitor the gaze of others, point to objects or events to share interest, and show toys to others. These behaviors have a distinct sharing quality to them. For example, the young infant may point to an airplane flying over head, and look to the parent, as if to say, "do you see that!"

In contrast, young children with autism have particular difficulties in jointly attending with others. They rarely follow another's points, do not often shift their gaze back and forth from objects to people, and do not seem to share "being with" the caregiver as they watch and talk about objects, people, or events. They also tend not to "show" a toy to the parent.

3) Does the child imitate others? Typical infants are mimics. Very young infants can imitate facial movements (e.g., sticking out their

continued on page 62



Special Bikes for Special People

A wide choice of
bikes, colors and
adaptive equipment
for people with
special needs.

165 Martell Court, Keene, NH 03431
Tel: 603-358-0438 • Fax: 603-358-0453
www.haverich.com

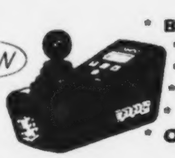
Circle #39 or visit www.eparent.com/adinfo

The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair



- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made in U.S.A.

Circle #35 or visit www.eparent.com/adinfo

continued from page 61

tongue). As early as 8-10 months, mothers and infants say the same sounds one after another, or clap or make other movements. Indeed, imitation is a major part of such common infant games as pat-a-cake and So Big ("How big is baby? Soooo big!" as infant raises hands to sky).

Young children with autism, however, less often imitate others. They show less imitation of body and facial movements (waving, making faces, playing infant games), and less imitation with objects.

4) Does the child respond emotionally to others? Typical infants are socially responsive to others. They smile when others smile at them, and they initiate smiles and laughs when playing with toys and others. When typical infants observe another child crying, they may cry themselves, or looked concerned. Somewhat older infants may crawl near the person, pat, or in other ways offer comfort. These latter behaviors are suggestive of empathy and are commonly observed among children in the second year of life.

In contrast, children with autism may seem unaware of the emotions of others. They may not take notice of the social smiles of others, and thus may not look and smile in response to other's smiles. They also may ignore the distress of others. Several researchers have now shown that when an adult feigns pain and distress after hitting herself with a toy, or banging her knee, young children with autism are less likely to look at the adult, or show facial concern.

5) Does the baby engage in pretend play? Someone once noted that "play is the work of children." Young children love to pretend-to be a mother, father, or baby, to be a firefighter or police officer. Although children start to play with toys around six months or so, play does not take on a pretend quality until the end of the first year. Their first actions may involve pretending to feed themselves, their mother or a doll, brush the doll's hair, or wipe the doll's nose. Nearer their second birthday, children engage in truly imaginative play as dolls may take on human qualities of talking or engaging in household routines. Children may pretend that a sponge is a piece of food, a block is a hat, or a plastic bowl is a swimming pool that contains water.

The play of children with autism may be lacking in several ways.

In contrast, the play of children with autism may be lacking in several ways. The young child may not be interested in objects at all, paying more attention to the movement of his hands, or a piece of string. If interested in toys, only certain ones may catch his interest, and these may be used in a repetitive way that is not consistent with how most children would play with the toy. They may be more interested in turning a toy car upside down and spinning the wheels than pushing the car back and forth. Overall, pretend qualities are nearly absent in the play of children with autism under 2 years of age.

It is important to note that in each of the 5 areas we have flagged, we are most concerned with behaviors that are absent or occur at very low rates. The absence of certain behaviors may be more difficult to pinpoint than the presence of atypical behaviors. But concerns in any of the above areas should prompt a parent to investigate screening their child for autism. Several screening measures are now available, and information from the screener will help to determine if the parent should pursue further evaluations. If the parent is convinced their child has autism, then they should seek an evaluation with an expert in autism. Most likely, this evaluation will involve an interview with the parents to obtain a complete developmental history of the child, and direct observations of the child in different situations.

Luckily, Timmy and his parents were able to get the diagnosis of autism before Timmy's third birthday. They began intensive treatment with Timmy, and he made immediate progress. They are hoping for the best outcome, and feel confident that his early diagnosis was critical in getting him the help he needs to reach his potential.

Dr. Connie Kasari is a Professor in the Division of Psychological Studies in Education in the School of Education & Information Studies at the University of California, Los Angeles. She has engaged in research on children with disabilities for over 20 years, and currently has two federally funded projects on interventions with young children with autism and their families.

Connie Wong is a doctoral student in the Division of Psychological Studies in Education at UCLA. Her interests are in preschool-based services for children with autism, and the effectiveness of different teaching methods with these children.

Students with Disabilities and Graduation Exit Exams

LEVELING THE PLAYING FIELD

By Louise G. L. Nelson and Ann P. Turnbull

Andrew Fry is a hard working, 18-year-old young man with autism who attends a high school in Indiana. He receives individual assistance in math, English (reading) and writing. Andrew's dream is to become an employee at a natural history museum. Michelle, Andrew's mother, is concerned that Andrew will not be able to fulfill his dream. To gain employment at a museum, Andrew will need to have at least a standard high school diploma. To receive a standard diploma, Andrew must achieve appropriate grades in all of his classes and pass the state's graduation exit exam.

With the help of appropriate accommodations, Andrew successfully participates in the general education setting and is completing Indiana's "Core 40" program, the first step towards graduating with a standard diploma. This academic program requires students to choose from a list of specific classes each with assigned credits. Students are responsible for maintaining a C grade average in at least 40 core course credits across the major academic areas. The next step is to pass the state's graduation exit exam, I-STEP+. Although there are other options for high school graduation in Indiana, Andrew and his family believe this program would help him achieve his dream.

Michelle does not think she knows all of the possible exam accommodations that could be made available to Andrew, nor does she believe that these adjustments have been offered during IEP meetings. She thinks that if she knew where to find more information she might be able to push for more specific exam accommodations for Andrew.

To level the playing field in these cases, these students are allowed to receive accommodations during testing.

Most parents dream of the day their adolescent graduates from high school with a standard diploma. The diploma signifies that a student has met all of the school, district, and state requirements. For students with special needs, earning a standard diploma usually means that they will have better education and job opportunities after high school.

In some states, the dream of earning a diploma is becoming harder to achieve. Out of 50 states, 15 require all students to complete specific high school classes with passing grades and pass a minimum competency or graduation exit exam which varies from state to state. Some states have other options for gaining standard diplomas, but many families think students with special needs should be given equal opportunities to take and pass their state or district's graduation exit exam. To level the playing field in these cases, these students are allowed to receive accommodations during testing. Unfortunately, parents are not often given information about the types of allowable and helpful accommodations available. The following questions and answers can help them learn about and promote the best possible accommodations for their adolescent with a disability.

Why do students with special needs participate in graduation exit exams?

Graduation exit exams belong to a family of assessments or tests called large-scale assessments. The exams measure students' learning at the state or district level and almost every state and many school districts have their own assessments. The purposes for these tests range from measuring students' performance to making sure that students are learning what the

continued on page 64

continued from page 63

state and/or district believe they should know as a result of a high school education.

Congress passed three pieces of legislation to help measure achievement. The Improving America's Schools Act and Goals 2000: Educate America Act together emphasize higher academic expectations for all students, improved student performance and more thorough measures of student achievement. A third piece of legislation, the Individuals with Disabilities Education Act (IDEA), makes sure that students with special needs are included in this national push for higher expectations and improved student performance by requiring states to include all students in statewide assessments. (See resources to find additional information.)

In an effort to conform to all three acts, 19 states have gone a step further and have mandated graduation exit exams. Students must pass these exams to receive a standard diploma. 15 of these 19 require all students to pass the graduation exit exam: Alabama, Arizona, Florida, Georgia, Indiana, Louisiana, Maryland, Mississippi, Nevada, New Mexico, New York, North Carolina, South Carolina, Tennessee, and Virginia. Three states, Minnesota, New Jersey and Ohio, do not require some students with special needs to take the graduation exit exam to receive a standard diploma, deferring to each student's individual education plan (IEP). Texas has an alternate exam that students with special needs must participate in to receive a diploma.

In some states there are alternate exams available, but in most cases these are only for students who work primarily on life skills and other education skills that are not in the general education curriculum.

Why is it helpful to include students with disabilities in graduation exit exams?

Before legislation specific to expectations was enacted, the levels of expectations for students with special needs, as compared to their peers, varied. Most of the time, the expectations were lower and sometimes they varied, even between schools in the same district. In addition, teachers, districts and states were also not held accountable for what they taught these students. These low levels of accountability allowed students with special needs to graduate with a diploma, but many of these students were not prepared for life after high school.

These students did not have the skills their non-disabled peers had, so they were not as readily employed. To combat these minimal expectations and lack of educator accountability, schools, districts and states are now required to include the scores of students with disabilities with all other students who take the same assessment. This pushes schools, districts and states to recognize that students with special needs must be taught the same core curriculum and be given the opportunity to learn the same information as their peers.

How can parents argue for improvements in the quality of instruction?

The biggest impact that parents can have in their child's education is to become involved, to be active monitors of what is taught in the classroom. By learning about their state's and district's expectations for all students, parents can help make sure that what is taught in the classroom meets requirements. Title I of the Elementary and Secondary Education Act specifically identifies parent involvement as a crucial part of improved instruction for all students. (http://neighborhoodlaw.org)

The website of the Center for Law and Education (http://www.cleweb.org) has several articles on how parents can make sure their child is learning. The RMC Research Corporation (http://www.rmcres.com) includes a piece explaining what parents can do to make sure that their child's school holds high academic expectations for their students. All of these articles recognize the importance of a parent's active participation in their child's education as a basis for improving instruction.

Do all students, regardless of their disability, take the same graduation exit exam?

Students with disabilities in the 15 states identified earlier have the opportunity to take the same graduation exit exam as their peers. In some states there are alternate exams available, but in most cases these are only for students who work primarily on life skills and other education skills that are not in the general education curriculum. To show advancement in learning, these students need an assessment that is more individualized. Alternate exams assess the knowledge and skills of this student group through processes including, but not limited to, individual interviews (one-to-one teacher student interviews about the student's accomplishments), portfolios (a collection of the student's work that shows the student's broad range of abilities) and adapted assessments (assessments that have been altered in length, material given, answer format). Texas is the only state that offers the alternate exam as a way for students with special needs to earn a standard diploma.

Table 1

Accommodations from Across the States

The Four Areas Presentation Response Setting Timing/Scheduling Descriptions The oral presentation or the written appearance of the assessment. Neither presentation method disqualifies the exam by paraphrasing, shortening, or otherwise altering the exam. The student's method of conveying his or her answers. The student's answers must be scripted, typed, or otherwise recorded exactly as the student stated them. The location or setting where the student takes the exam. The location must be monitored. The amount of time a student is allowed to complete either sections of the exam or the entire exam.

Examples:

1) A student with poor vision is provided with an exam that has larger print.

2) The instructor reads the directions and questions out loud to the students.

Examples:

A student says out loud which "bubble" he/she wants marked and the scribe fills in the bubble.

2) A student types their answers to an essay question into a word processor

Example:

The student takes the exam in a room with no other students.

A small group of students take the test in a room to themselves.

Example:

The student is allowed extended time to complete the written section of the exam.

The student can take as many breaks as he/she needs to be able to concentrate on the exam.

Can parents ask for modifications or accommodations to the graduation exit exam?

Before answering this question, the terms modifications and accommodations need to be defined: they are two different forms of support that help students with special needs become an active part of the general education classroom.

Modifications are changes made to instruction or materials that help students work towards the same goals as their peers. For example, modifications to an exam might include the deletion of some items on the test, abbreviated instructions, or a shortened essay question. Modifications to large-scale assessments are not allowed. Because of this, states are now recognizing the need to assess the skills of students who are unable to complete the large-scale assessment. Therefore, the use of these alternate assessments for identified students has increased.

Accommodations are changes to the academic environment or the presentation of the material and are allowed in varying degrees by states and districts on graduation exit exams. Examples include small group or individual settings, extended time to complete the exam, the repetition of instructions when needed, or students being allowed to tape record their responses to an essay question. Appropriate accommodations, typically the same ones that help the students succeed in the classroom, can help students perform their best on a graduation exit exam.

What accommodations can parents request?

The accommodations allowed for graduation exit exams vary by state and sometimes by district. It is important that any accommodation match the student's needs and cannot be interpreted as an unfair advantage offered to the student on the graduation exit exam. The National Center on Education Outcomes (NCEO) gathered information about large-scale assessments and grouped the different types of accommodations into four areas: presentation, response, setting, and timing/ scheduling. Not every state grants accommodations in each of these areas, but it is important for parents to know what other states and districts allow so they can advocate for additional appropriate accommodations for their adolescent. The following table gives brief descriptions of each of the areas.

How can parents effectively promote test modifications for their adolescent with special needs?

Just as parents advocate for their adolescent with special needs in the classroom, they need to do the same for accommodations during graduation exit exams. To be effective, parents need to be knowledgeable about the state requirements for these tests. Table 2 provides basic information on the graduation exit exams of 15 states, including a state contact person or department who can answer questions. To help their student prepare for the test, parents can:

- Set and maintain high expectations for their adolescent and ensure that all pro-fessionals involved with him or her do, too.
- Ask about the four accommodation areas included in Table 1. Often, the student must be receiving a specific support in the general education classroom to be provided with accommodations during the graduation exit exam.

continued on page 68

Table 2

Graduation Exit Exams: Participating States, the Exams, and Contact Information*

State	Name of exam	Number of opportunities given to pass exam and/or additional information	State education web site	Contact person or office
Alabama	Alabama High School Graduation Exam ASGE)	6 with additional opportunities post-graduation if necessary. Additional information is found at http://www. alsde.edu/general/Great_Expectations.pdf	http://ww.alsde.edu/	Mabrey Whetstone, coordinator (334) 242-8114 Or "Mastering the Maze" speced@aisde.edu
Arizona •••	Arizona Instrument to Measure Standards (AIMS)	5 Specific testing for students with disabilities is being investigated.	http://www.ade.state.az.us/	Academic Standards & Accountability Tel: (602) 542-5031
Florida	Florida Comprehensive Assessment Test - Sunshine State Standards (FCAT-SSS)	7 For FAQs see: http://www.firn.edu/doe/sas/fcat/pdf/fcatfaq1.pdf Also, see question 17.	http://www.firn.edu/doe/	Florida Department of Education Janet Adams (850) 487-3164, Suncom 277-3164 adamsj@mail.doe.state.fl.us Jane Silveria (850) 487-1603, Suncom 277-1603 silverj@mail.doe.state.fl.us
Georgia	Georgia High School Graduation Test	5 (see) http://www.doe.k12.ga.us/sla/ret/ghsgtabout.html For specific legal information see http://www.doe.k12.ga.us/legalservices/160-4-2-.37.pdf	www.doe.k12.ga.us	Phil Pickens, Director, Division of Exceptional Students, at (404) 656-3963. E-mail: ppickens@doe.k12.ga.us.
Indiana	GQE (Graduation Qualifying Exam)	5 For FAQs see: http://doe.state.in.us/publications/pdf_istep/gradexam02.pdf	http://ideanet.doe.state. in.us/	Jon Barada jbarada@doe.state.in.us Room 229, State House Indianapolis, IN 46204-2798 (317) 232-6616
Louisiana	Graduation Exit Examination for the 21st Century (GEE-21)	English/Language Arts and Math: 7 opportunities. Science and Social Studies: 4 (beginning in 2004).	http://www.doe.state.la.us/DOE/asps/home.asp http://www.doe.state.la.us/DOE/Assessment/GuideSelectAccom.pdf	Leslie Lightbourne (225) 342-3633
Maryland •••	Maryland High School Assessments	Re-takes decided on an individual basis.	http://www.msde.state.md.us/ or http://mdk12.org/mspp/high school/what_is/factsheet.html	School and Community Outreach Office 410-767-0600 or 1-888-246-0016
Mississippi •••	SATP (end-of-course) exams in U.S. History from 1877, English II, Biology I, Algebra I	3 times per year until passing score is achieved. For specific information about the exams see: http://www.mde.k12.ms.us/public/IHF-2.htm	http://www.mde.k12.ms.us/	Mississippi Department of Education Office of Special Education at (601) 359-3498.
New Mexico	New Mexico High School Competency Exam	4	http://www.sde.state.nm.us/	The New Mexico State Department of Education at: (505) 827-5641

State	Name of exam	Number of opportunities given to pass exam and/or additional information	State education web site	Contact person or office
New York	Regents Examination Program	Until the student graduates or turns 21. For specific information on retesting: http://www.emsc.nysed.gov/ciai/testing/component.html	http://www.nysed.gov/	Eastern Regional Office 518-486-6366 Western Regional Office 716-821-7360 Hudson Valley Regional Office 914-245-0010 Long Island Regional Office 631-884-8530 New York City Office 718-722-4544
North Carolina * * *	"Exit exam of essential skills" In effect for students graduating in 2005. NC Test of Computer Skills	"Additional opportunities will be provided for those students who need them." http://www.ncpublicschools.org/student promotion/diploma req.html	http://www.ncpublicschools.org/	For more information on the involvement of students with special needs, see: http://www.ncpublicschools.org/parents/testingfaq.html and http://www.ncpublicschools.org/accountability/testing/policies/TestProg0001.htm
South Carolina	The High School Exit Examination (to be replaced in 2003)	4 http://www.myscschools.com/reports/exit2000/	http://www.sde.state.sc.us/	Susan DuRant, Director at 734-8806 sdurant@sde.state.sc.us
Tennessee * * *	Gateway Test end-of-course tests; Algebra I, Biology I. English II	Multiple opportunities to retake the exams. See: http://www.state.tn.us/education/ci/cigateendofcourse/cigatewqa.htm	http://www.state.tn.us/education/	Special Education Programs at 615-741-3340
Texas * * *	TAAS exit level tests or end-of-course tests. Alternate assessments are available to achieve a standard diploma. * * A specific test for students with disabilities will be introduced in 2005.	Multiple opportunities to retake the exams. Please see: http://www.tea.state.tx.us/student.assessment/resources/grad/eocgrad.html	http://www.tea.state.tx.us	The Student Assessment Division at (512) 463-9536. Ask for the division on students with special needs.
Virginia * * *	4/10 of the Standards of Learning (SOL) exams or acceptable score on the SAT II, ACT, CLEP,or the AP	No limit on additional opportunities	http://141.104.22.210/go/VDOE/	Anita Swan, head of Parent Resources at (804) 371-7420

---

* The data in this Table is current as of 9/25/02. Any states that have added Graduation Exit Exams to their curriculum since 12/01 have not been added.

* * Some colleges and universities use the TAAS exam as an entrance exam. If a student is exempt from the TAAS and wants to attend one of these colleges or universities, this student will be required to take the SAT.

* * Applicable to graduating classes where the freshman class begin in 2001 or after.

Andrew performs better in testing situations when he receives individual attention because the attention helps relieve test anxiety and the lack of distractions helps him to focus.

continued from page 65

- Review past graduation exit exams. These are often found on the state's education web site.
- Find out the testing procedures used in the state or district.
- Talk to their teenager about the test. Parents can stress the importance of the exam without instilling fears or raising doubts in the adolescent.
- Ask school personnel to help them interpret the results of the test.
- Talk about their adolescent's goals for the future, what necessary steps should be taken to meet those goals and determine whether there is an alternative to the graduation exit exam that better suits their adolescent's needs.
- Ask questions.

Students with special needs who live in the 15 states that have graduation exit exams are being held to the same high expectations as their general-education peers. Parents can help their teenager with disabilities to participate more confidently in the graduation exit exam by being well informed about the exam and by advocating for appropriate accommodations.

To date, Andrew has taken the I-STEP+ twice. When the results of his first attempt came back in January of 2001 and he had not passed the exam, Andrew was required to take remedial math and English classes during the second semester of his sophomore year. He was also required to take a summer school class specifically to help him prep for the I-STEP+ during his junior year. Before he took the exam in September 2001, Andrew chose to participate in one-hour review sessions that were held on the five days before the exam. He also worked with his private tutor on additional skills.

Michelle appreciates this extra support for Andrew, but she has been disappointed with the accommodations provided. Although Andrew was in the resource room when he took I-STEP+, he was still in a group setting. Andrew performs better in testing situations when he receives individual attention because the attention helps relieve test anxiety and the lack of distractions helps him to focus. The one accommodation offered to Andrew was to allow him to get up and walk around the room periodically. Michelle understands the necessity of I-STEP+ and why certain modifications cannot be made to the exam. She also knows that with appropriate accommodations—one-on-one instruction, extended time, additional breaks during the testing—Andrew is successful in the general education classroom. Michelle realizes that she must continue to work at bridging the gap between what is offered in the classroom and what is offered during the exam. EP

Louise Lord Nelson was a special educator in Indianapolis, IN for eight years. She is currently a doctoral candidate at the Beach Center on Disability at the University of Kansas.

Ann Turnbull is a Professor in the Department of Special Education and Co-Director of the Beach Center on Disability at the University of Kansas. She has authored 12 books and over 175 articles and chapters. She is the parent of three children, one of whom is an adult son with cognitive and mental health disabilities.

RESOURCES

Individuals with Disabilities Education Act (C.F.R. 34 § 1400 et seq.), http://www.ideapractices.org/law/index.php

Goals 2000: America's Education Act of 1994 (Public Law Number 103-227), http://www.ed. gov/ pubs/G2KReforming/

Improving America's Schools Act of 1994 (IASA), http://www.ed.gov/legislation/ESEA/brohure/iasa-bro.html

FairTest: The National Center for Fair & Open Testing, http://fairtest.org/index.htm

Public Agenda Online, http://www.publicagenda.org

Focuses On Special Education, http://www. edweek.org

Wrightslaw, http://www.wrightslaw.com

The Education and Research Network, http:// www.aera.net

The National Center on Education Outcomes, http://www.coled.umn.edu/NCEO/default.html

http://www.neighborhoodlaw.org/Title1program.htm, *by the Center for Law and Education*

http://www.cleweb.org/issues/title1/tool.htm, *by the Center for Law and Education*

Parents ask about standards, http://www. rmcres.com/famed/askabout/english/standard.html, *by The RMC Research Corporation*

PART TWO

Recognizing and Tracking Pain in Children with Developmental Disabilities

Sally Colatarci,
RN, MS, FAAMR and
Wendy M. Nehring,
RN, PhD, FAAN, FAAMR

AAMR

AAMR promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities.

There is a growing recognition that it is important to know how to recognize pain in children, especially non-verbal children with developmental disabilities, and ways to help manage the pain.

Parents know their child best and are the best advocates for their child and their child's pain management. As we state throughout this column, it is important to know how to assess whether your child is in pain, how bad the pain is, where the pain is located and what works best for your child's pain. (This latter point will be addressed more fully later in this series.)

Pain is an individualized experience. We all experience pain at some time in our lives and how that pain affects the quality of our life and what measures work to decrease or eliminate the pain will differ for every person.

Individuals have different ways of expressing their pain. If someone says that they are having pain, believe them, no matter what their cognitive ability, because they are experiencing pain.

There are no ideal assessment tools available for children with developmental disabilities, so it is important to find something that works best for your child. Research has shown that children with developmental disabilities are assessed less often for pain, have their pain level underestimated and are given less pain medication than children without developmental disabilities by health care professionals. However, hospitals and physicians' offices also have a new appreciation of pain in all patients and healthcare personnel are learning to be more sensitive to pain relief needs.

In this column, we will explain ways to recognize and assess pain, manage the pain and advocate for proper control of pain in children with developmental disabilities.

Recognizing and Assessing Pain

There are a number of ways that a child tells us that he or she is in pain. In infancy, that way is to cry, although it is often difficult to know where the pain is. As the child gets older, they

continued on page 70

This is the second in a monthly series written for EP Magazine by members of the American Association on Mental Retardation (AAMR).

A pictorial scale or a number scale may work for a child with higher cognitive functioning, whereas, for someone who is nonverbal and with low cognitive functioning, a facial scale for infants may be more appropriate.

continued from page 69

learn words that they can use to tell us they have pain, where the pain is located and to describe how the pain feels (e.g., stabbing, sharp, dull, all over, etc.). A child with developmental disabilities may not be able to do this. It is important that parents be able to recognize when their child is in pain. A list of these physical signs are given below:

- ☐ Increased crying, that may be inconsolable
- ☐ Facial grimaces not regularly seen
- ☐ Increased physical movements which may include self-injurious behaviors (e.g. biting)
- ☐ Rocking and/or head banging
- ☐ Increased sounds, such as grunting
- ☐ Less playful
- ☐ Change in eating habits
- ☐ Change in mood, depressed, sad, irritable, withdrawn, and/or less cooperative
- ☐ Flushed skin

A health professional may also note that there may be a rise in temperature, an increase in blood pressure and a higher heart rate.

Children who are verbal and know words to use for pain may choose not to tell a parent that they are in pain. This may be because they think the parent already knows that they do not know what to do and/or they are scared that if they tell they will have to see a health care professional, go to the hospital and/or have a procedure (e.g., a shot) that will further be painful. Other children may not know the words to use to tell about their pain and are poor reporters of where it hurts and how much it hurts. Parents should be aware that some neurological conditions affect pain sensors and the sensation of the pain for the child is altered.

Here are some questions that you can ask your child:

- ☐ Tell me about a time when you had pain before. Where did it hurt? How bad did it hurt? For how long did it hurt? Do you know what started the pain?
- ☐ Who do you tell when you have pain?
- ☐ What helps to take away the pain?
- ☐ What do others do to help you with the pain?
- ☐ Are there any equipment (e.g. sign boards) or other ways that you use to tell others about your pain?

Here are some questions that parents need to consider and be able to answer when asked by health professionals?

- ☐ Tell me about your child's pain experiences.
- ☐ How do you know that your child is in pain?
- ☐ What signs does your child show and/or what words does your child use?
- ☐ What ways does your child communicate that he or she is in pain?
- ☐ Does your child let you know when he or she is in pain?
- ☐ How much pain is your child having when they tell you?
- ☐ Is it when the pain first begins or after the child has been in pain for awhile and it is getting worse?
- ☐ How do you deal with your child's pain?
- ☐ What do you do for him or her?
- ☐ Does your child do anything first for him or her self to stop or reduce the pain?

What do health professionals need to know about your child's pain and how to manage it when you are away?

It is important that parents know the answers to these questions and are able to advocate for their child. Writing this down and having copies will help the parents avoid having to repeat themselves or try to remember every detail, each time someone new sees their child.

There are also a number of instruments used to assess pain in children without developmental disabilities. These scales vary depending upon the child's age and range from identifying the degree of pain by picking out a picture of a face among a range of faces (e.g. Whaley and Wong's Faces Scale) to indicating on a scale, say from 1-10, with 10 being the worse pain imaginable.

A pictorial scale or a number scale may work for a child with higher cognitive functioning, whereas, for someone who is nonverbal and with low cognitive functioning, a facial scale for infants may be more appropriate. For children who are nonverbal, the appropriate pain assessment tool depends on the child's level of cognitive deficit.

Relying only on doing "what the doctors tell me to do" will help your child in only a limited way. Being sensitive to your child's signals and learning how to differentiate the meaning of these signals will be important to optimally managing your child's pain. Maintaining a diary and/or a handout that describes your child's signals of pain, diversion activities and appropriate pain management will help your child when you cannot be present. Understanding your child's pain and how to manage it will help decrease anxiety, worry and sleeplessness for children as well as their parents. EP

> Maintaining a diary and/or a handout that describes your child's signals of pain, diversion activities and appropriate pain management will help your child when you cannot be present.

Sally Colatarci, RN, MS, FAAMR is Director of Nursing at Matheny School and Hospital in Peapack, New Jersey, a residential facility for persons with profound disabilities. She is currently the Nursing Division President for AAMR. She can be reached at scolatarci@matheny.org.

Wendy M. Nehring, RN, PhD, FAAN, FAAMR is Acting Associate Dean for Educational Services and Professor at Southern Illinois University Edwardsville, School of Nursing in Edwardsville, Illinois. She is currently Chair of the Health Promotion and Prevention Committee for AAMR. She can be reached at wnehrin@siue.edu.

AAMR
444 North Capitol Street, NW
Suite 846
Washington, D.C. 20001-1512
Telephone: 202/387-1968 or 800/424-3688
Fax: 202/387-2193
http://www.aamr.org

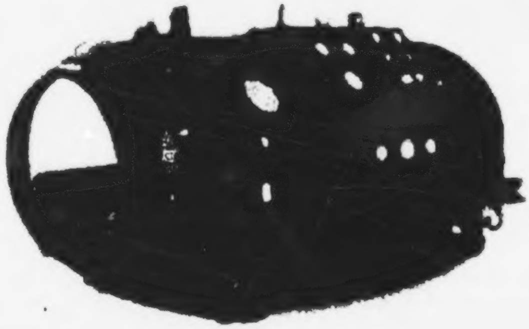
CINCINNATI HYPERBARICS

Hyperbaric Oxygen Therapy

"Your comfort and well-being are our prime concern"

Unique Alternative Approaches
Cincinnati Hyperbarics has a unique blend of both orthodox and alternative approaches.

State of the Art Equipment
This is a physician owned, operated, and staffed facility. Dr. Ted Cole works with each person to help maximize the benefits from their treatments at the center.



Exceptional Care
Dr. Ted Cole evaluates every patient. He designs and supervises every patient's course of therapy and monitors every patient's progress, and is able to provide other treatments to accelerate and enhance each person's recovery.

Cincinnati Hyperbarics Phone (800) 667-5395 or (513) 563-4321 - Fax (513) 563-3131
www.cincinnatihyperbarics.com - info@cincinnatihyperbarics.com

EP neither endorses nor denies the effectiveness of hyperbaric oxygen therapy. For Editor-in-Chief statement see our Contents page.
Circle #65 or visit www.eparent.com/adinfo

Fashion In a Snap

By Lori Ostrover

While there is a fashion revolution in such groups as plus sizes and maternity clothes, the same has not occurred in the disability community. Judi Cohen, the owner of the adaptable clothing line WeBehave.Com, is determined to make a difference. She feels very strongly that fashion for people with disabilities should not be compromised. *"Especially for kids; there are still ways to look 'cool' and in style," she says.*

Cohen has taken an eighties fad and made it one of the best sellers in her company. Called Lastic Laces, they eliminate the need for anyone to ever have to tie their own shoe.

These extra curly, stretch cord laces come in goofy colors and were originally designed for challenged individuals, however, they crossed over into the mainstream.

Now they're back being helpful to individuals with disabilities. Lastic Laces make any shoe into a comfortable slip-on. This is beneficial since no one has to bend over, use his or her arms, hands, upper body or eyes. You can log onto the website www.WeBehave.Com to order.

Pip Squeakers makes shoes for kids under the age of five. Every time the child takes a step the heel of their foot will set off a squeak. Because parents can always hear where the child is stepping, it is possible to give the child greater freedom and a better sense of independence. They are made of silky, durable fabric.

One particular sandal comes in blue or red and has a 'funky' star-pattern along the sole. An added bonus, when children are in the early stages of walking, the noise is enticing and makes them eager to take more steps.

Markell Shoes have created a true orthopedic sneaker for children with ankle-foot orthoses (AFO) called the TM2000. The sneaker is constructed with added depth and greater width, which makes it easy to slip the foot and the AFO device into the shoe comfortably. Shoes from other companies like Quality Care Therapeutic Shoes customize their products for the more mature individual.

The shoes are heated up with a heat-gun and then conformed to a person's foot. This is great for children whose feet might be turned inward as well as adults with diabetes.

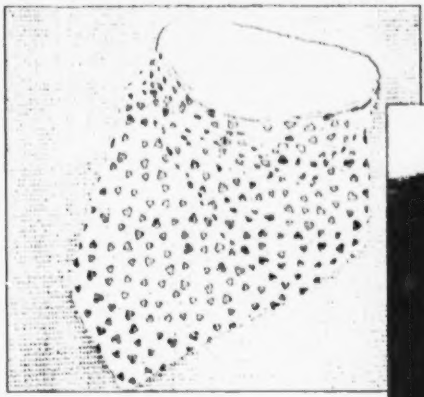
Lastic Laces from WeBehave.Com

Know Your Fabric

Choosing the right fabrics should always be taken into consideration. If a person has perspiration problems it is important to wear more natural fibers which allows more breathing room. The right fabric will also let perspiration evaporate so an individual does not feel damp or chilled.

Cotton is great in the heat. It is much more absorbent than synthetic fabrics such as polyester and nylon, which tend to trap moisture, which is also important for people who have drooling problems.

There is a way to make a bib look more stylish. Companies such as David's Collection, Able Apparel, WeBehave.Com and Adrian's Closet make 'bandana' bibs. They are made of cotton fronts and are backed with breathable fabrics such as goretex



Bandana Bib from Adrian's Closet (hearts)

Bandana Bib from Able Apparel

and terry cloth. They keep the individual dry without creating additional sweating problems. The bibs also prevent clothes from getting soggy and consequently, cut down on illness due to sudden chills.

WeBehave.Com makes this 'bandana' style bib in an attractive blue denim. Able Apparel manufactures them in plaid patterns of pastel colors. They even make a bib out of gold or silver lame for formal occasions. Adrian's Closet makes one that is covered in little hearts and is pleated at the neckline, giving it more of a stylish accessory look. These products add to the dignity of the wearer.

Wool and fleece fabrics are effective in keeping warm from cold weather. Able Apparel makes a multicolor fleece jacket, which contains an easy and accessible back closer. The color combinations are designed to blend in with more conventional garb.

They also make thumbless mittens out of fleece that are slipped onto the hand through zipper openings. Rolli Moden makes half finger gloves that mimic gloves worn by motorcyclists, but are designed for people in wheelchairs. They're made of leather with gel padding to protect the palms of individuals confined to wheelchairs. The finger tabs allow the glove to be removed from the hand with ease.

The weight of fabric is also important when it comes to adaptable clothing. Heavy fabrics like canvas and corduroy can be exhausting when worn frequently. This particularly affects individuals who are required to wear protective headgear.

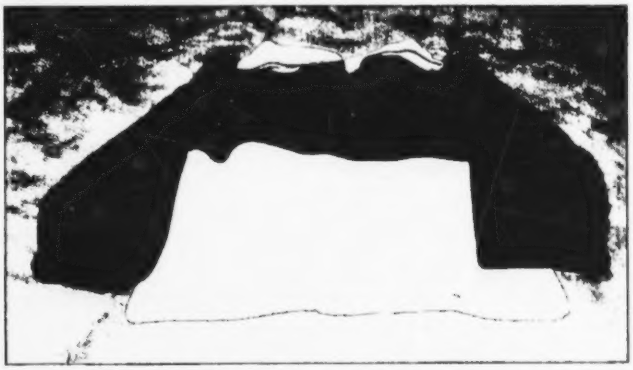
There has been a misconception that headgear had to be hard, bulky and heavy. Plum Enterprises' Inc. soft ProtectiveWear® line offer customized headgear for individual's needs, at any age.

The ProtectaCap® has additional shock absorption and is virtually weightless. The soft fabrics make it machine washable. It provides kid safety and an increased self-esteem.

The company also makes a ProtectaHip® that has the same consistency of the headgear along with a fully elasticized waistband. Recently, the American Society on Aging made it the Outstanding Product Design of the Year, declaring, "it is a simple solution to a serious problem."

Knit fabrics as opposed to woven are more comfortable, especially when sitting because they don't bulk up as much. Nylon is actually a better fabric when seated. Adrian's Closet makes a pair of nylon pants with zippers from top to bottom on each side of the pant leg. The elastic waist prevents bunching and the smooth fabric provides comfort. These pants are considered by many to be very stylish and practical at the same time.

Thumbless Mittens from Able Apparel



Multi-color fleece jacket from Able apparel. The strip of velcro goes all the way down the back

For more information about adaptable clothing check out the book Dressing Tips and Clothing Resources for Making Life Easier by Shelley Schwartz. It is filled with interesting information for the special needs community and is available in the EP library.

Get Creative

Everyone has his/her own

continued on page 74

continued from page 73

requirements and desires when looking for adaptable clothing. The best way of establishing an individual's style is to modify existing or standard clothes. An individual can buy the latest fashions and make magic by adding the personal touch and aides needed to make their clothes adaptable.

If shirts that button down are troublesome, sew the buttonholes closed and attach some velcro squares where the holes were. On the other panel, underneath the buttons, attach the other side of the velcro. This gives the satisfaction of dressing independently and the buttons on the outside of the shirt keep the same look.

Do the same with zippers on pants or skirts. Try putting large loops of bias tape inside the waistband of an individual's bottoms making them much easier to pull up. The exact location and length will vary depending on their needs.

Jill Kamphaus, happy as always, wearing one of her many owned ProtectaCaps®

Rolli Moden's half finger gloves

Nylon zipper pants from Adrian's Closet

PERSONAL INDEPENDENCE

THE EVERGREEN CENTER prepares students to lead meaningful lives in the community. Through an individual educational program combining basic skills and behavior development,our students learn to lead more independent lives as integrated members in the community.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631

Serving students with developmental, medical and behavioral needs since 1981.

Circle #32 or visit www.eparent.com/adinfo

HMS Enables Active Learning

HMS School for Children with Cerebral Palsy serves children, ages 2-21, who have multiple disabilities resulting from cerebral palsy or traumatic brain injury. Skilled, compassionate staff and consultants provide individualized interdisciplinary programs that enable each child to flourish and learn.

Day & Residential Programs • Special Education
Physical & Occupational Therapies • Speech/Language Therapy
Music Therapy • Nursing & Nutrition Services • Medical Support
Therapeutic Recreation

State-of-the-Art Assistive Technology:
Augmentative/Alternative Communication
Computer Access
Environmental Control
Powered Mobility

For more information contact:
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy
– FOUNDED IN 1882 –
4400 Baltimore Ave., Philadelphia, PA 19104
215-222-2566 • Fax: 215-222-1889
www.hmsschool.org
E-Mail: admin@hmsschool.org

Member: NAPSEC • Pennsylvania's Alliance of Approved Private Schools

Circle #41 or visit www.eparent.com/adinfo

Use items of clothing bought in any apparel store, open up the back seam and put velcro all the way down. This is a great trick for an individual with limited upper body movement. Sometimes cutting out a v-neck for more room to pull over the head will make a top look cool.

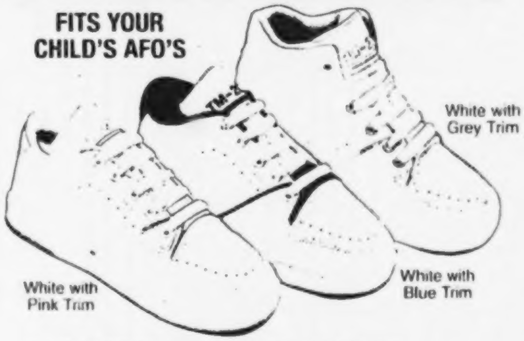
DRESSING
TIPS
CLOTHING
RESOURCES
for making life easier
SHELLEY PETERMAN SCHWARZ

Shelley Peterman Schwarz's insightful book, full of tips and trends "for making life easier".

Add personal touches and fashion flair and find a nice pendant or even a key chain to attach at the end of any zippers located on garments, including jackets. This will enable much more ease pulling the zipper shut. Craft stores are great to browse through to find stylish trimmings. Perhaps an individual might want to add rhinestones to a particular shirt. This look is very popular among all kids. Ribbons, puffy paints and patches are a few other options, which might appeal to a child. These ideas will help save money. Family service agencies or the Department of Rehabilitation might reimburse for clothes if it means independence and tax deductions may be available. EP

How to order these products:

PPP Enterprises
www.WeBehave.Com (1-800-770-4325)
Pip Squeakers
www.pipsqueakers.com (908-500-2596)
Quality Care Therapeutic Shoes
www.qualitycaredme.com (909-825-5213)
M.J. Markell Shoe Co.
www.markellshoe.com ((914-963-2258)
David's Collection
www.davidscollection.com (410-668-0068)
Able Apparel
www.ableapparel.com (1-888-688-ABLE)
Adaptations by Adrian
www.adrianscloset.com (1-800-831-2577)
Rolli Moden
www.rolli-moden.com (1-800-707-2395)
Plum Enterprises
www.plument.com (1-800-321-PLUM)

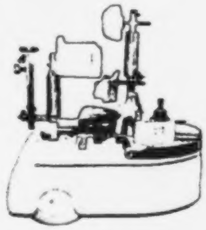
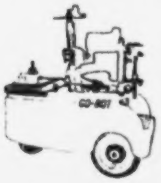
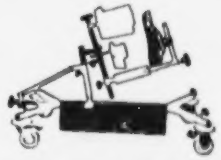
TM2000
SERIES
by MARKELL
Order Online at www.markellshoe.com
FITS YOUR CHILD'S AFO'S


The TM 2000 Series has the following features:
- Symmetrical straight last.
- Added depth - 3/16" (5mm) deeper than our conventional straight last shoes, to accommodate orthotics, AFO's and internal modifications.
- Extended contours firm enough to provide support and stability.
- Whole and half sizes from Infants' 5 to Youths' 4.
- Widths - A choice of Medium and Wide.
- Removable cushioned insoles

M.J. MARKELL SHOE CO., INC.
504 Saw Mill River Road, P.O. Box 246, Main Station, Yonkers, N.Y. 10702
TEL: (914) 963-2258 • FAX: (914) 963-9293

Circle #49 or visit www.eparent.com/adinfo

Early Childhood Mobility
Mini Go-Bot's

Century Stander

Stanford Standard
Note: Standing frames work with either Go-Bot

Yellow Go-Bot

GB-I Gait Trainer
(can be customized)
Innovative Products, Inc.
1-800-950-5185
Web Site: www.iphope.com

Circle #43 or visit www.eparent.com/adinfo

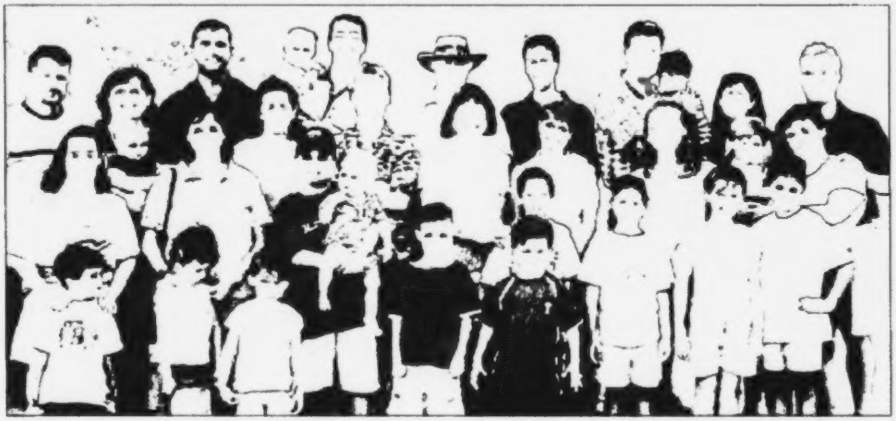
A Celebration of a Life!

Yvonne Catherine Fitzpatrick Murphy

Mrs. Yvonne Catherine Fitzpatrick Murphy of Atlanta, Georgia died October 6, 2002 at the age of 66. She fought her battle against esophageal cancer with great faith and dignity; she was truly a woman of valor. Mrs. Murphy was the wife of Frank J. Murphy, President and CEO of the EP Foundation for Education, Inc. (EPFE). In addition to Frank, she is survived by seven daughters, six sons-in-law, 17 grandchildren and a host of friends.

The Murphys' youngest daughter, Karen, has Down syndrome, and both Yvonne and Frank have been active parent advocates, first with the National Down Syndrome Congress and, more recently, with EPFE. Yvonne was on hand for the World Congress & Exposition on Disabilities in Atlanta in both 2000 and 2001, and was sorely missed at the just-concluded conclave in Orlando, Florida.

A true lady, Mrs. Murphy was gentle, soft-spoken and charming. ***All of us at EP will miss her very much.***



This picture was taken on the beach at Pawley's Island, South Carolina, on August 2, 2002. It is of Frank and Yvonne Murphy and their entire family, 32 in all. Across the front, left to right: Michael Oliver, Rachel Miller, Kasey Farrell, John Bleekrode, Blake Farrell. Next row back: Karen Murphy, Joan Miller, Kevin Bleekrode, Brendan Bleekrode (in his arms,) Emily Oliver, Catherine Oliver, Mary Beth Bleekrode, Sarah Oliver. Next row back: Phelim Farrell, Sandy Farrell, Page Yvonne Farrell (in her arms,) Mary Oliver, Joey Bleekrode, Yvonne Murphy, Julia Ehlers, Katie Bleekrode, Janice Givens, Timmy Bleekrode (in her arms,) Laura Bleekrode. Back row: Lyndon Oliver, Murphy Givens (in Rich's arms), Rich Givens, Frank Murphy, Barry Ehlers, Mark Miller, Ben Miller (in his arms), Kim Bleekrode.

A Randomized, Controlled Trial of a Community-Based Support Program for Families of Children with Chronic Illness: Pediatric Outcomes

Children with chronic illnesses, who are at increased risk of developing mental health problems, can reduce that risk by participating in community-based support programs, according to a recent study.

Conducted in Baltimore, MD, the study involved 136 mothers and children aged seven to eleven years. Each of the children had one of four conditions: diabetes mellitus, sickle cell anemia, cystic fibrosis, or moderate to severe asthma.

The study included a control group, and used four methods of mental health evaluation. These were the Personal Adjustment and Role Skills Scale III, the Self-Perception Profile for Children, the Revised Children's Manifest Anxiety Scale, and the Children's Depression Inventory.

continued on page 78

You think about your child's positioning day and night. So do we.

With the Jenx™ Animal Collection for daytime therapeutic positioning, and their Dreama™ Sleep System for night, Bodypoint Designs brings perfect positioning to the whole body…24/7/365.

JENX

Distributed by BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104
In Canada, call Advanced Health Care Products, Tel. 800-265-9830

Circle #20 or visit www.eparent.com/adinfo

continued from page 77

The 15-month, community-based program was provided by child life specialists and "experienced mothers." It included contact through telephone calls, face-to-face meetings, and special events involving the family. Child and parent mental health reports were taken as they entered the study, then one year later, to determine mental health at baseline and any changes that took place during the study period.

A cutoff score was chosen to indicate maladjustment; the experiment found that the percentage of children in the control group who fell in the maladjustment range at baseline increased from 15 percent to 21 percent over the course of the project. Conversely, the percentage of children in the experimental group who fell in the maladjustment range was nearly cut in half: 19 percent of experimental group children fell in the maladjustment range at the beginning, compared to 10 percent by the end. In particular, children with low physical self-esteem at the beginning of the program experienced a more pronounced effect than children whose physical self-esteem was moderate to high before the intervention project.

The experiment showed that family support intervention has positive effects in promoting mental health and adjustment in children with these four chronic health conditions, and especially in children with low physical self-esteem. Because the program was comparably helpful to children with each of the four disorders included in the experiment, the results suggest that this type of community-based intervention may be helpful to children with all kinds of chronic illnesses. EP

The experiment was conducted by Robin G. Chernoff, MD, Henry T. Ireys, PhD, Katherin A. DeVet, PhD, and Young J. Kim, PhD.

For more information on the experiment, visit http://archpedi.ama-ssn.org/issues/v156n6/ abs/ poa10379.html or contact Robin G. Chernoff, MD, Department of Pediatrics, The Johns Hopkins School of Medicine, 600 N Broadway, Baltimore, MD 21287 (e-mail: rchernof@jhmi.edu)

WenzeLiteRe/hab

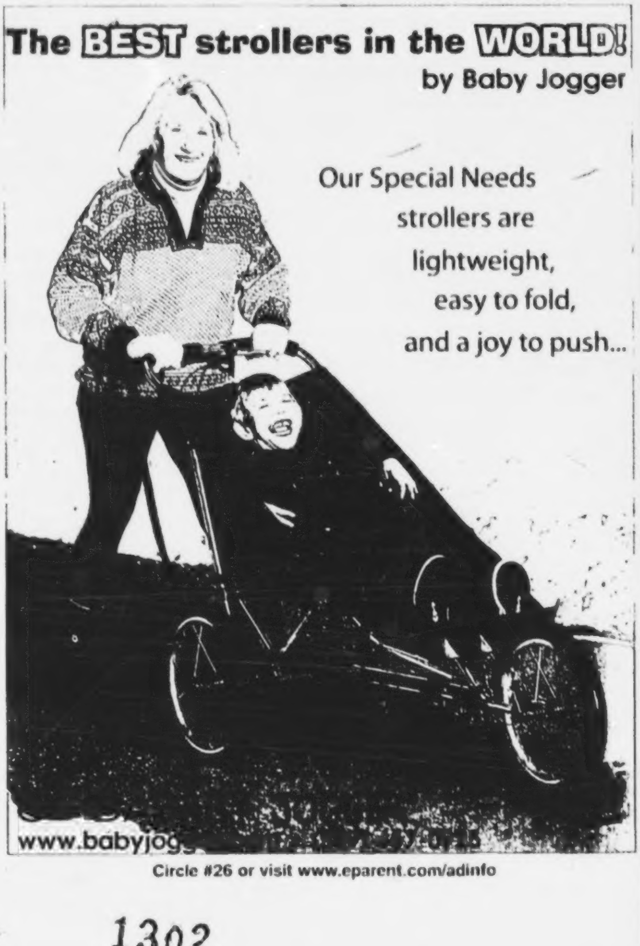
Providers of Pediatric Rehab Equipment

SEATING SYSTEMS
BATHING CHAIRS
STROLLERS
STANDERS
WALKERS

CALL US AT
718-768-8002 / (800) 706-9255
For information about our
FREE EVALUATION PROGRAM

www.wenzelite.com • e-mail: wenzelite@aol.com

Circle #46 or visit www.eparent.com/adinfo

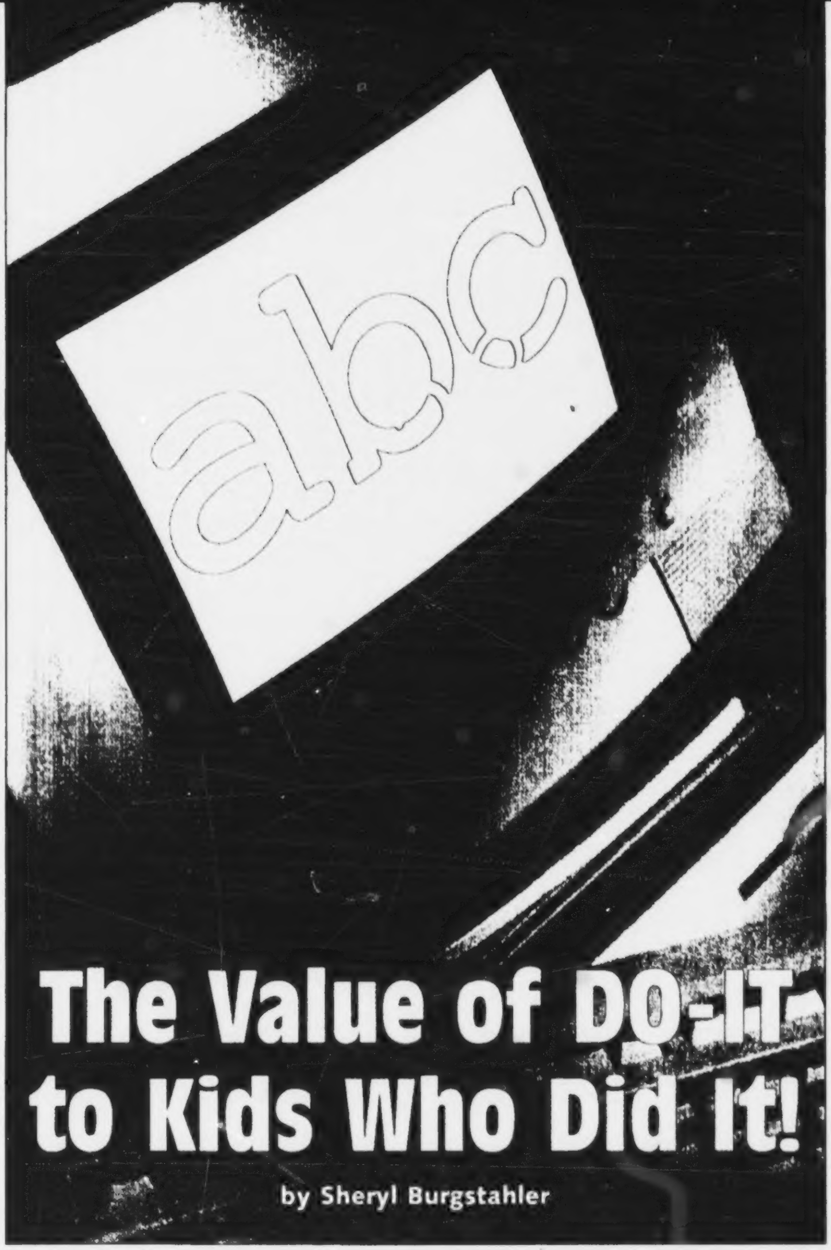


The BEST strollers in the WORLD!
by Baby Jogger

Our Special Needs strollers are lightweight, easy to fold, and a joy to push...

www.babyjog

Circle #26 or visit www.eparent.com/adinfo



The Value of DO-IT to Kids Who Did It!

by Sheryl Burgstahler

Individuals with disabilities experience far less career success than their non-disabled peers. However, as in the general population, differences in achievement diminish with more education. Only 16 percent of people with disabilities with less than a high school diploma participate in the labor force, compared to 30 percent of those who complete high school, 45 percent of those with some postsecondary education, and 50 percent of those with at least four years of college. Without a postsecondary degree or job experience, people with disabilities have a harder time finding challenging careers.

High-tech careers are particularly desirable because of advancements in assistive technology that provide access to computers and scientific equipment for people with a variety of disabilities. This column shares information about a program that promotes college and career success and lessons learned that can be applied by those who work with young people who have disabilities.

THE DO-IT SCHOLARS

DO-IT (Disabilities, Opportunities, Internetworking, and Technology) at the University of Washington (UW) in Seattle sponsors a program that is creating leaders, mentors and role models for the next generation. The DO-IT Scholars program uses computers, the internet, assistive technology, summer study programs, internships and other activities to prepare young people with disabilities for college and careers. Most students begin participation in the DO-IT Scholars program during their sophomore year of high school.

COMPUTERS, ASSISTIVE TECHNOLOGY AND THE INTERNET

DO-IT Scholars are provided with computer equipment, any needed assistive devices and internet access in their homes. They use information resources and communicate year-round with each other, project staff and mentors. When asked about the most valuable skills they gained through DO-IT participation, more than 80 percent of past Scholars rated computer and internet skills as the

continued on page 80

Dr. Sheryl Burgstahler is the director of the DO-IT (Disabilities, Opportunities, Internetworking, and Technology) program. DO-IT is funded by the US Deptartment of Education, the state of Washington and many other organizations. DO-IT serves to empower young people with disabilities as they transition to college and careers through the use of computers, assistive technology and the Internet. "Tech Talk" is designed to address practical ways of integrating technology into educational, work and home environments. Dr. Burgstahler will also answer readers' questions through this column. Please send correspondence to: Dr. Burgstahler, University of Washington, Box 354842 Seattle, WA 98195; fax: (206) 221-4171; e-mail:sherylb@u.washington.edu.

Camphill Special School
Children's Village
A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- **Pennsylvania Approved Private School**
- **Waldorf Curriculum (Member of AWSNA)**
- **Both Day & Residential Programs Available**

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236
www.BeaverRun.org

Circle #21 or visit www.eparent.com/adinfo

Discover
***New England Village**, Inc.*
"A community rich with opportunity, sharing and growth"

Established as a non-profit corporation in 1972, New England Village is a warm, caring, stable and secure environment where young adults with mental retardation can lead a high quality lifestyle with opportunities for growth and friendship.

Our campus, set on 80 beautifully wooded acres just 25 miles south of Boston, offers attractive contemporary style homes and townhouse apartments. Learn about our full range of residential options, extensive vocational and educational programs, and wide spectrum of recreation and social opportunities. We invite you to meet our dedicated and caring staff and to speak with other families about our Village.

Call (781) 293-5461, x110 or write Judy Andracchio, Admissions Coordinator, to arrange your personal visit or request our brochure. We invite private and state-sponsored referrals.

***New England Village**, Inc.*
664E School Street • Pembroke, MA 02359
781-293-5461 • www.newenglandvillage.org
info@newenglandvillage.org

visit www.eparent.com/adinfo

continued from page 79

most valuable. These skills enhance their academic and career opportunities as well as their ability to communicate efficiently with mentors and peers. One Scholar summarizes the greatest impact of the program this way: "DO-IT has shown me that information is empowerment and that through computer and social networking there is virtually free access to information for everyone."

MENTORING AND PEER SUPPORT

DO-IT Scholars use electronic communications and personal meetings to connect with postsecondary students and career "mentors." "Mentors [show] how you can be successful in your chosen field despite your disability," shares one Scholar. Most of the mentors have disabilities themselves. Through mentors, students learn how to be more independent, to advocate for themselves and to persevere.

Experienced Scholars mentor younger participants. The communication and leadership skills they develop extend beyond the Scholar program. One parent reports that her son, a Scholar with attention deficit disorder (ADD), helped another child with ADD "by taking the boy to register for high school and showing him around so he will know where things are on the first day of class."

DO-IT staff and mentors pose discussion questions to the group and share information about school, internships and other useful resources. Smaller groups focus on specific access challenges. For example, in the "doitvi" group, Scholars and mentors share technological and other strategies to compensate for a visual impairment. After participating in DO-IT for several years, one Scholar summarizes, "I've been prepared for my future in academic, social and employment aspects. I'm excited and eager to see what the world has to offer now that I've participated in the DO-IT program, not to mention all the great friendships and fun times I've had." DO-IT has shown that peer and mentor support, traditionally provided in person, can be delivered via a supported electronic community on the internet.

SUMMER STUDY

The DO-IT Scholars program involves summer study sessions held during two consecutive summers on the University of Washington campus. Scholars learn how to maneuver through a large campus, request disability-related accommodations, get along with a roommate and succeed in college courses. They begin to explore different career fields.

Scholars report developing social skills and self-determination skills that lead to success in academics, employment and adult life. They also become more aware of the challenges other students face as they work with peers who have a wide variety of disabilities, including sensory impairments, mobility impairments, learning disabilities, chronic health conditions and psychiatric disorders.

In a science lab, for example, it is not unusual to find a blind student working with someone without the use of his hands to perform bypass "surgery" on a sheep heart. The two learn quickly how, using the combination of skills they possess, they can follow the instructions and get the job done. Everyone needs to participate in DO-IT activities. One past Scholar says that participation in DO-IT helped him to realize "that I can have a normal adult life and that my disability really should not stop me from pursuing a career that is interesting to me."

DO-IT does not end on the last day of the on-campus program. As soon as Scholars return home, they log on to the internet to continue their friendships. "It's kind of like going to summer camp," reports one Scholar, "but to a certain extent I don't ever have to go home."

WORK-BASED LEARNING

During the third year, Scholars have the option to return to the DO-IT summer study program as interns. They learn about all of the work that goes on behind the scenes to make the program a success. They participate on panels to share their experiences with the younger participants, and in other ways help them transition successfully to college. During the year, opportunities to participate in social get-togethers and conferences, as well as internships in high-tech companies, are available to the Scholars.

SIGNS OF SUCCESS

The DO-IT Scholars program has demonstrated success in helping young people with disabilities pursue college and careers. Of the 168 Scholars who have graduated from high school, 151 (90 percent) are currently attending or have attended college. Twenty-six have graduated from college and five are enrolled in graduate school. Two have completed Masters degrees. Their fields of study and employment include biology, business, chemistry, computer science, ecology, engineering, mathematics, nutritional sciences, pediatric psychiatry, physical therapy, physics, premedicine and speech and hearing sciences. One Scholar who is blind completed degrees in mathematics and computer science and is now a Rhodes Scholar at Oxford.

When Scholars were asked which specific skills the DO-IT summer study program helped them develop, 65 percent reported social skills, 59 percent reported career/employment skills and 47 percent reported academic skills. When Scholars were asked what specific skills computer and internet activities helped them to develop, 67 percent reported academic skills, 61 percent reported career/employment

continued on page 85

LINCOLN CENTER | for the Performing Arts

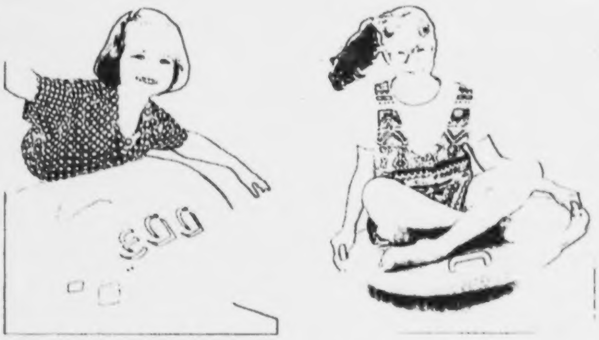
We bring the best of the performing arts to everyone

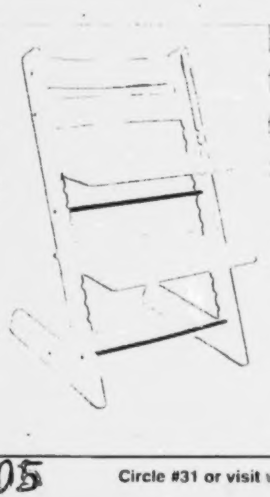
Lincoln Center is proud to offer its Passport Program for children with disabilities.

Please call **212.875.5374** to find out about free weekend performances and our Meet-The-Artist School series.

Visit **www.lincolncenter.org** for accessibility information from Lincoln Center's Programs and Services for People with Disabilities.

Circle #47 or visit www.eparent.com/adinfo





We Like Making Kids Happy ...

Send For Free Catalog

equipment shop

P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094

E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #31 or visit www.eparent.com/adinfo

Getting information from

EP advertisers is

MUCH FASTER ONLINE!

It's as easy as a click
of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and FASTER!

FREE Information from Advertisers CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in EXCEPTIONAL PARENT.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.

Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
16	ABILITY CAMP	98
19	ADAPTIVEMALL.COM	85
17	ANNANDALE VILLAGE	6
20	BODYPOINT DESIGNS, INC.	77
21	CAMPHILL SPECIAL SCHOOL	80
22	CHARLES C THOMAS	49
65	CINCINNATI HYPERBARIC	71
23	COLUMBIA MEDICAL	11
25	CONVAID	15
24	COTTING SCHOOL	58
27	CROTCHED MOUNTAIN	54
28	CYBERONICS, INC	36-38
	CYCLETOTE CORP	89
29	DYNAVOX SYSTEMS LLC	27
30	EDEN FOODS, INC	9
200	EP LIBRARY BOOK CLUB	40
200	EP LIBRARY PAGES	94-95
199	EP SUBSCRIPTION	17-18
31	EQUIPMENT SHOP	81
32	EVERGREEN CENTER	74
33	FREEDOM DESIGN	7
34	FREEDOM MOTORS USA	45
35	GLOBAL POWER SYSTEMS INC	61
36	GULDMANN, INC	86
37	H.D.I.S.	46
38	HARD MANUFACTURING	16
39	HAVERICH ORTHO-SPORT, INC	61
18	HEARTSPRING	43
40	HERTZ SUPPLY CO., INC.	47
41	HMS SCHOOL	74
	HOUSE AD	82
43	INNOVATIVE PRODUCTS	75
44	KENNEDY KRIEGER	C3
46	LAWYERS, INC	21
47	LINCOLN CTR FOR PERFORMING ART	81
48	LITIGATORS, INC	33
49	M.J. MARKELL SHOE COMPANY	75
50	MELMARK	C2
	NEW ENGLAND VILLAGE	80
51	NOVARTIS NUTRITION	23
52	OCEAN HYPERBARIC CENTER	53
53	REAL DESIGN	57
54	RED BARN ENTERPRISES	88
55	SAMMONS-PRESTON	13
42	SNUG SEAT	19
56	SIGMA TAU	1-2
57	SOUTHPAW ENTERPRISES, INC	89
58	STEWART HOME SCHOOL	85
26	THE BABY JOGGER COMPANY	78
59	VAIL PRODUCTS	C4
60	VERIZON	5
61	VIEWPOINT MOBILITY LLC	58
62	WENZELITE MEDICAL SUPPLY	78
63	WOODBURY PRODUCTS	86
64	WORLD CONGRESS	34-35

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms,
300 North Zeeb Road, Ann Arbor, MI 48106

EP
has the
information an
"Exceptional
Parent"
like you
needs

EP
Exceptional
Parent

Subscribe

on our

website:

www.eparent.com

and save

$5.00

For telephone

orders

call:

877-372-7368

To start your subscription to EP today, fill out the card near the front of this magazine or log on to www.eparent.com

---

EP MAGAZINE Free product & service information order card* **NOVEMBER 2002**
FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______

Address ______

City ______ State ______ Zip ______

Phone ______ Fax ______

E-mail ______

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No

If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist ^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist

^{10}☐ Other (please indicate) ______

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No

If Yes, are you a: ^{13}☐ Other (please indicate) ______

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No

If yes, please explain ______

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

***CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: April 30, 2003**

BNOV2

EP MAGAZINE Free product & service information order card* **NOVEMBER 2002**
FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent?
☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______

Address ______

City ______ State ______ Zip ______

Phone ______ Fax ______

E-mail ______

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No

If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist ^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist

^{10}☐ Other (please indicate) ______

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No

If Yes, are you a: ^{13}☐ Other (please indicate) ______

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No

If yes, please explain ______

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

***CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: April 30, 2003**

BNOV2

To start your subscription to EP today, fill out the card near the front of this magazine or log on to www.eparent.com

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

aNo Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

Exceptional Parent is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others who are providing a richer life for themselves and for their children.

Exceptional Parent's MISSION IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS
Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE
GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

continued from page 81

skills and 51 percent reported social skills. One Scholar summarizes, "I think the greatest impact for me is, it helps me to understand more about myself and the people in the real world. I have learned how to adapt to society without thinking that I am disabled, that I am useless."

When parents were asked to what degree DO-IT enhanced their children's lives, the highest-ranked items were interest in college, perception of career options, self-esteem and self-advocacy skills. Parents ranked social skills highest, followed by career/employment skills and academic skills as those most developed through summer study. Of the computer/Internet aspects of DO-IT, career/employment skills ranked highest, followed by academic and social skills. As summarized by one parent, "My son has benefited greatly from the DO-IT program. He was able to realize that many other students had to struggle through school. DO-IT camps allowed students to bond and the computer networking allowed them to continue to support each other through the year. He did not think much about his future until he attended DO-IT Camp. He came home talking about his college plans, with confidence that he could manage it. DO-IT has also helped my son get a part-time job for his first year of college. ... He has achieved a level of independence we never thought possible."

LESSONS LEARNED

What lessons can be learned from the DO-IT experience that can help educators, program developers and families help young people with disabilities transition to college studies and careers? Successful strategies include:

COMPUTER AND INTERNET ACCESS

Give students with disabilities access to computers, assistive technology, electronic communication and internet resources at an early age. Make sure computing resources in schools, such as computer labs and educational software, are accessible to students with disabilities.

PEER SUPPORT

Help connect college-capable young people with disabilities with other teens who have disabilities. Encourage relationships among students with a wide variety of disabilities; these connections can help them understand their own challenges and solutions and gain insights into the potential and accommodation needs of others. Being more aware of challenges faced by other people can help them become leaders and mentors to others.

continued on page 86

1309

Adaptivemall.com™

Shop
On-line!

Tim's daughter Carrie.. a young adult with Down Syndrome

We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.
Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #19 or visit www.eparent.com/adinfo

Special Care for Special People

Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #58 or visit www.eparent.com/adinfo

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at
DISCOUNT PRICES!

As a service to our customers, we offer **FREE SAMPLES** of disposable youth briefs and pull ups.

Save up to 50%

Call **1 800 777 1111** 24Hrs
WOODBURY PRODUCTS, INC.
Order online at: **www.woodburyproducts.com**

Circle #63 or visit www.eparent.com/adinfo

Guldmann
Ceiling lifts

Easy to use ceiling mounted transfer systems for physically challenged individuals.

- **Battery operated**
- **Used for lifting from wheelchair to bed, floor or bathroom facilities**
- **Used independently or with assistance**
- **Mobile floor models also available**

Call today for a free evaluation of your transferring requirements and for the ceiling lift representative nearest you.

Guldmann, Inc.
1-800-664-8834
813-880-0619
813-880-9558 FAX

Circle #36 or visit www.eparent.com/adinfo

continued from page 85

MENTOR SUPPORT

Create situations where young people with disabilities can gain access to role models who have disabilities and are successful in demanding careers. Promote mentoring relationships between young people and adults with disabilities. Employ the internet to sustain these relationships.

COLLEGE PREPARATION

Have students visit college campuses, learn about resources and become experts on the assistive technology and other accommodations they need before the end of their high-school years. Offer programs that bridge the gap between high school and college, between two-year and four-year schools and between undergraduate and graduate studies. Encourage them to take high school courses, such as math and science, that will maximize their options for academic majors when they go to college.

WORK-BASED LEARNING

Provide opportunities for young people to participate in paid and unpaid work experiences. Through internships, job shadows, volunteer work and other work-based learning experiences, they can prepare for future employment, learn how to self-advocate for accommodations and practice job-related skills. Seeing their own potential for stimulating careers will also motivate them to succeed in school. **EP**

Dr. Sheryl Burgstahler is the director of the DO-IT (Disabilities, Opportunities, Internetworking, and Technology) program. DO-IT is funded by the US Department of Education, the National Science Foundation, the state of Washington and many other organizations. DO-IT serves to empower young people with disabilities as they transition to college and careers through the use of computers, assistive technology and the Internet. "Tech Talk" is designed to address practical ways of integrating technology into educational, work and home environments. Dr. Burgstahler will also answer readers' questions through this column. Please send correspondence to: Dr. Burgstahler, University of Washington, Box 354842 Seattle, WA 98195; fax: (206) 221-4171; email: sherylb @u.washington. edu

Further information about DO-IT programs and resources can be obtained at:
DO-IT
University of Washington, Box 355670
Seattle, WA 98195-5670
doit@u.washington.edu
http://www.washington.edu/doit

organizational spotlight

IFOPA: International Fibrodysplasia Ossificans Progressiva Association

By Marilyn Hair, Vice President

Dr. Fred Kaplan and Thirteen-year-old Tiffany Linker Mark

In 1692, French physician Guy Patin wrote, "I saw a woman today who finally became hard as wood all over." This is the earliest clinical description of fibrodysplasia ossificans progressiva (FOP), a rare genetic disorder that causes bone to form in muscles, tendons, ligaments and other connective tissues. Bridges of extra bone form in characteristic patterns, progressively restricting movement. In FOP, the body produces an extra skeleton that immobilizes the joints of the body. FOP affects approximately 2,500—one in two million people—worldwide.

Children with FOP appear normal at birth, except for a congenital malformation of the great toe. Typically, during the first decade of life they form painful fibrous nodules over the neck, back and shoulders, which mature into bone in a process known as heterotopic ossification. FOP progresses along the trunk and limbs, replacing healthy muscles with normal-appearing bone. Any attempt to remove the extra bone, however, results in explosive new bone formation. People who have FOP experience different rates of new bone formation; in some the progression is rapid, in others more gradual. Often, by their mid-20s, people who have FOP are immobilized by an extra skeleton of FOP bone and use a wheelchair full-time.

In 1987, then-29-year-old Jeannie Peeper had never known of anyone else with FOP. She asked her doctor at the National Institutes of Health, Michael A. Zasloff, MD, PhD, for the names of other patients so she could correspond with someone else who had FOP. She was given 18 names, the complete list of living FOP patients known to the NIH. Jeannie composed a questionnaire asking for each person's date of diagnosis, hobbies, interests and a few other details. With eleven responses, she began a newsletter, the FOP Connection. The next year, 1988, the International FOP Association was incorporated, and has since expanded to a membership of 300 in 42 countries. Members and supporters raise and donate funds which allow the IFOPA to fund research at a major university and support a small office staff.

continued on page 88

continued from page 87

The International FOP Association has three missions:

- supporting medical research to find treatments and a cure for FOP;
- educating physicians, patients and the public;
- providing support to patients and their families.

Medical Research

In 1991, Dr. Zasloff and orthopedic surgeon Dr. Frederick S. Kaplan founded the FOP Molecular Biology Laboratory at the University of Pennsylvania School of Medicine. Research conducted at the FOP Laboratory has yielded profound insights into bone formation and FOP; additionally, it may shed light on other bone-related conditions such as arthritis and osteoporosis. Funding sources include the National Institutes of Health, the Ian L. Cali Fund for FOP Research, the Stephen L. Roach/ Whitney Weldon Fund, and the International FOP Association. FOP patients from all over the world over travel to the University of Pennsylvania for clinical visits with Dr. Kaplan and his colleagues. Researchers can access the FOP community through the IFOPA, which offers a patient population needed for research.

Education

Rare disorders are often not recognized or correctly diagnosed, and it is not uncommon for people with FOP to be misdiagnosed and subjected to harmful surgery or chemotherapy. In 1985, for example, a prominent surgeon amputated the entire right arm and shoulder of a little girl whose condition he had misdiagnosed. The IFOPA works to disseminate information about FOP to doctors, patients, families, and the public.

A breakthrough came in February 1998 when an article about FOP, "A Few Hundred People Turned to Bone" by Thomas Maeder, appeared in The Atlantic Monthly. The next year, FOP was featured on television on ABC's 20/20 and in an hour-long segment, "The Skeleton Key", on the BBC's Horizons science program.

The Internet is a wonderful educational tool that has given anyone and everyone access to obscure medical information. Through the IFOPA website, http://www.ifopa.org, doctors can learn about FOP and patients can find each other. Parents of symptomatic but undiagnosed children have found information, which has led their doctors to a correct diagnosis of FOP.

Support

With a condition as rare and debilitating as FOP, patients and their families feel terribly isolated. IFOPA'a third mission is to provide support to FOP patients and their families. The group continues to publish FOP Connection, the quarterly newsletter begun in 1987, as well as an abbreviated newsletter, Milestones, directed to donors.

A private e-mail group, foponline, allows instant electronic access to the FOP community. A South American mother of a young child with FOP appealed to the e-mail group for guidance to help her child through a

With the Creepster Crawler, You Can Watch Your Child Crawl for the First Time!

Children lacking head control, the ability to roll over or belly crawl have gained mobility with the ***Creepster Crawler.*** Using this light, innovative device, hundreds of children around the world are crawling, working more productively with their therapists, and gaining a head start to more advanced mobility in the future.

The ***Creepster Crawler*** is an ideal solution for youngsters with debilitating conditions such as ☐ Spina Bifida ☐ Down Syndrome ☐ Cerebral Palsy ☐ TBI, and ☐ developmental delays. Children with tracheostomies and G-Tubes also are successful users of the ***Creepster Crawler***.

The ***Creepster Crawler***'s frame has a padded platform that can support a parent or therapist from above, making it easier to work with the child on weight-bearing, weight-shifting, reaching and creeping. Front shoulder, chest and rear straps can be adjusted for individual fit.

Please visit our Worldwide Web site at www.redbarn-enter.com for additional details and a video demonstration of the ***Creepster Crawler***.

Call for a Brochure!
1-800-577-1317
Fax:1-602-242-9211
or email us at info@red-enter.com

RedBarn
ENTERPRISES

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.redbarn-enter.com**

CAUTION: Children should not be left unattended in the Creepster Crawler.

Circle #54 or visit www.eparent.com/adinfo

painful flare-up, and community members responded with treatment suggestions and moral support. A 17-year-old wrote that she wants to move away from home to go to college and wondered how others schedule and pay for personal care attendants. Several FOP peers told how they find the accommodations and assistance they need to live on their own.

The IFOPA offers resources and consultation about assistive technology and funding sources through its L.I.F.E. Committee, Living Independently with Full Equality. IFOPA publications include What is FOP? A Guidebook for Families and What is FOP? Questions & Answers for the Children, both on the IFOPA website, and Overcoming Obstacles: A Catalogue of FOP Resources.

Three International FOP Symposia have been held in Philadelphia. The most recent, in 2000, was attended by 150 doctors and scientists and 94 persons with FOP and their families. For some it was a sweet reunion, while for others the Symposium provided their first opportunity to meet other people with FOP. Being together as a community feels like coming home. The bond of common experience and understanding is overwhelming. It's a glimpse of what heaven must be like, the place we are understood like nowhere else. EP

For more information, contact:
International Fibrodysplasia Ossificans Progressiva Association (IFOPA)
Jeannie Peeper, President
PO Box 196217
Winter Springs, FL 32719-6217
Phone: 407-365-4194
E-mail: together@ifopa.org
Website: http://www.ifopa.org

southpaw enterprises®
DAYTON, OHIO U.S.A.

Providing Hundreds of Sensory Integration and Development Product Solutions!

Therapists, educators, parents and physicians acknowledge Southpaw as the industry leader in providing high-quality, state-of-the-art and safe Sensory Integration and Developmental products. Our products are made to the strictest standards of quality. We also strive to make our products fun while providing you with the innovative and safe solutions you require for great therapy.

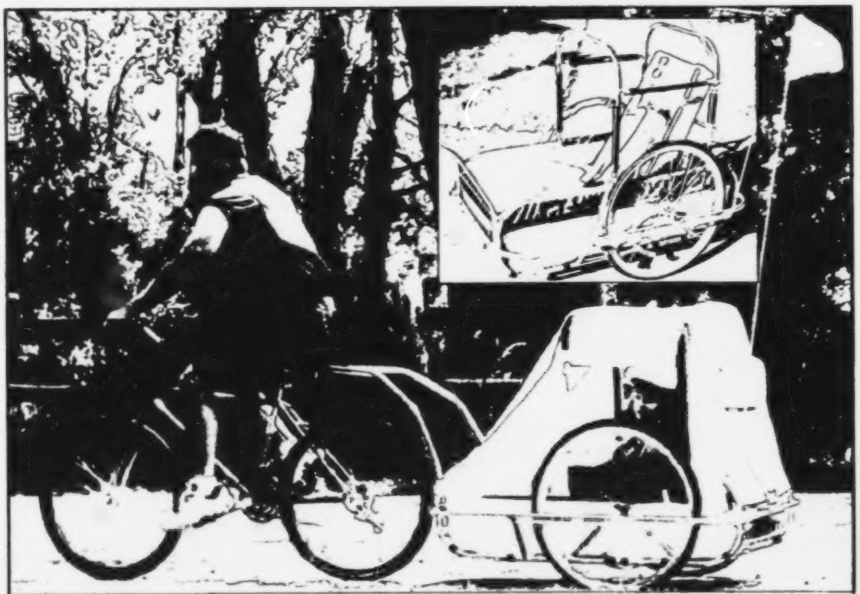
Phone toll free:
1-800-228-1698

Or contact us from our website:
www.southpawenterprises.com

Call for our FREE full line product catalog!

Southpaw Enterprises
P.O. Box 1047
Dayton, OH 45401-1047

Circle #57 or visit www.eparent.com/adinfo



Enjoy the out-of-doors together with a

CycleTote® Bicycle Trailer
Running Stroller

1-800-747-2407 www.cycletote.com

Satisfaction Guarantee/Lifetime Warranty

visit www.eparent.com/adinfo

Third Annual World Congress

Thousands of individuals with disabilities, parents, caregivers, physicians and healthcare providers gathered at the Third Annual World Congress and Exposition on Disabilities in Orlando last month. They came to hear more than 200 sessions ranging from autism to adaptive sports to empowerment.

Keynote addresses from the Commandant of the U.S. Marine Corps, James L. Jones, himself the parent of a Fragile X daughter and Francis Collins, leader of the Genome Project were interspersed with formal and informal gatherings in every available area of the Orlando Convention Center.

The theme of the conclave was sounded by the head of the Department of Education's Special Education Division, Robert Pasternak. He said, "that the challenges and opportunities facing the disabilities community makes this an exciting time but one that requires much work and sacrifice. But in the end, we will have a brighter future."Also addressing the convention was Florida Governor Jeb Bush.

However, it was the attendees who provided the real motive power for the event, bringing their problems, answers and goals to every educational discussion. Many sessions featured overflowing crowds and spread out to adjoining rooms when the allotted time was over. As one healthcare professional from the Bahamas told a physician panelist, "I came here to learn and it will take me a year to digest all I have taken in."

Visitors to the sprawling exhibit area met a profusion of providers from large companies and individuals who were caregivers and saw a need that they could meet.

As Joseph M. Valenzano, Jr. said during one session; "two years ago I had a dream and today I am looking at a reality."

The Fourth World Congress on Disabilities will be held in Orlando, next September 18-20, 2003.

RESS & EXPOSITION ON DISABILITIES
WCD

At left: Dr. Francis Collins, MD, PhD, during his keynote speech.
Above: Dr. Robert Cicco, MD, a.k.a. "Bobbles the Clown" preforms on the showroom floor.

& Exposition on Disabilities

IN ORLANDO

Clockwise from top left: Dr. Peter Stackpoole, PhD, MD, of the University of Florida Medical School; Dr. Vidya Gupta, MD, MPH, of the Child Development Center of Morristown Memorial Hospital in NJ; Ridgeway School is honored as Educational Institute of the Year by James L. Jones, Commandant of the U.S. Marine Corps (Center). At his right is Duane Arbogast, Principal. At extreme left is Leslie Twohig, a parent. Michele Overend, special ed teacher and Joseph M. Valenzano, Jr., EP President and CEO are at right.

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

PART XIII

ORAL HEALTH: A VISION FOR THE FUTURE

by Clive Friedman, DDS

Beginning in 2001, *EP Magazine* has published a series of articles related to oral health. Specific articles have looked at topics including oral hygiene, the relationship of the mouth to the rest of the body, diseases of the soft tissue, orthodontics and managing behaviors. The question now asked is, where do we go from here?

Even within the United States and Canada, access to care continues to be a major problem for many individuals. Barriers to care include, finances, discrimination, prejudice; fear, anxiety, inability to articulate need and lack of perceived need, among other issues. Professional barriers include inadequate undergraduate education, insufficient staff training, failure to recognize diversity and the failure to see oral health in the context of illness and disability. Dr Sanford Fenton and Dr Carlton Horbelt articulate these problems extremely well in their October 2002 article. They explain the role the parent, guardian or direct support professional (DSP) can play in advocating for improved care by being V (vigilant) I (involved) and P (persistent). Experts also have to take on a greater responsibility in approaching this oral health issue. One of the biggest areas of need is in improving the undergraduate and postgraduate education of dental professionals and encouraging them to undertake this kind of care.

Dr Steven Perlman started the unique initiative of the Special Olympics Special Smiles Program, which has resulted in oral health screenings at more than 70 Special Olympics events across the US and at 12 international sites. These screenings have helped to identify the remarkable lack of care provided to only one segment of the special-needs population, and those who do not have access to Special Olympics would be even less likely to receive care. Special Olympics also helps to expose many health professionals who would otherwise never have that opportunity to people with disabilities.

Will we ever see a time when neither physical nor social discrimination is present and all persons with disabilities can access health care equitably? Perhaps this is an unanswerable question. But this article will articulate a vision of oral health in an attempt to alert readers to alternative possibilities with the need for improved access to total dental health care.

Health is a resource for living, not the object of living. It is a positive multidimensional and dynamic concept that can be described as the inclusion and balancing of an individual's social, emotional, spiritual and mental needs. Oral health is no less a dynamic concept without which overall health is not possible. Let's for one moment envision a situation where one is not fighting for basic access to care, but where instead it may be possible not only to access care but also to provide care that allows for the quality of life that everyone deserves, especially in one of the wealthiest countries of the world.

The oral cavity is composed of varying competing and complementary systems. Most dentists concentrate on the teeth, jaws and gums. Equally important are communication, swallowing, eating, breathing, and expression of emotions, all using various facial muscles. The anatomy of the oro-facial complex consists of small parts that should fit together in a cohesive unit, functioning in harmony and balance. Thus, problems in this area can occur with a malfunction in any of these systems. For example, a neurological impairment such as cerebral palsy, trauma or multiple sclerosis can affect anatomy, development, speech and nutrition. Neuromuscular impairments like muscular dystrophy or genetic conditions like Down syndrome or Prader-Willi syndrome will have a major impact on the oro-facial complex.

When taken in the greater context,

the need for evaluation and treatment of these systems together begins to make more sense. Thus an integrated approach to care is needed, where one can begin with an early diagnosis and initiate strategies for early intervention.

Let's look at a child with Down syndrome as an example. Prior to one year of age s/he could be evaluated with regard to muscle function and developmental growth patterns. Risk assessment for future problems should be evaluated. If muscular function was affecting speech development, therapy could be initiated to help speech development and tongue placement. Extra-oral massage could be initiated to simulate normal oral physiological development. Risk assessment evaluations for development of periodontal (gum and bone) disease as well as decay could be completed. Appropriate interceptive preventive programs could then start at an early age. This would require the coordinated and integrated efforts of a dentist, speech pathologist, occupational therapist, nutritionist, hygienist, physiotherapist and possibly a social worker. The presumption is that appropriate funding is available and that the agencies responsible are on board.

In most U.S. and Canadian systems of care, a person seeks treatment from each individual specialist as needed. Parents and caregivers will get information from each person and then must integrate all the information received on their own. Many times they receive contradictory information and have difficulty in determining whom to follow or believe. What if centers of excellence were established where an individual could receive a complete diagnosis of needs and establish treatment objectives for long-term care? Isolated areas where this team approach is taken are currently available; however, they exist largely within major university settings. For many parents the complexities of accessing this type of care are both burdensome and complicated.

Perhaps dentists and other professionals could begin to create centers where they could coalesce in groups and create this type of comprehensive care program. They may be forced to respond to this only when the recipient of care—using VIP—demands it.

The technological age has enabled parents and professionals alike to access information at the click of a mouse. Although much of this information may produce overload, it has at least made more possibilities available and creates a knowledgeable recipient who can advocate for care and will no longer accept mediocrity. This improved knowledge can empower those involved in the decision-making process including parents, guardians and DSPs who are part of the team. This will improve the overall care and quality of health of all involved.

Wouldn't it be nice if, just for once, a parent, guardian or DSP did not have to be an advocate in order to get care, did not need to be Vigilant, Involved and Persistent—if there were a system where it was easy to access quality care. In the realistic North American paradigm in which we live, this does not seem possible in the near future—but without the dream, the future evaporates.

Oral Health America has identified a 10-year campaign for improved oral health for 22.5 million Americans who currently do not have access to care. The definition of "disability" in the social context is: "...the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers." The future would provide every opportunity for individuals to participate in community life within the full spectrum of possibilities. Following the VIP principle, we want more than mediocrity and minimal care. Let's strive for excellence. The few dental professionals who treat persons with disabilities cannot do this alone – we need your help.

EP Magazine has begun this process by publishing numerous articles on oral health. Let's continue this momentum and remember that each single whisper eventually adds up to a scream. EP

Dr. Friedman is a pediatric dentist in private practice in London, Ontario, Canada. He is currently President of the IADH (International Association of Disability and Oral Health) and a Clinical Associate Professor at the University of Western Ontario.

WWW.EPLIBRARY.COM

EP Exceptional Parent LIBRARY

THE SPECIAL NEEDS BOOKSTORE

AUTISM

THINKING IN PICTURES
My Life With Autism
TEMPLE GRANDIN WITH
A FOREWORD BY OLIVER SACKS

The author is a gifted animal scientist who has designed one third of all the livestock-handling facilities in the US. She is also autistic, a woman who thinks, feels, and experiences the world in ways that are incomprehensible to the rest of us. In this unprecedented book, the author delivers a report form the country of autism. Writing from the dual perspectives of a scientist and an autistic person, we learn how the country is experienced by its inhabitants and how she managed to breach its boundaries to function in the outside world. What emerges is a document that sheds light on the riddle of our common identity.

[illegible] $12.00

AUTISM IN THE EARLY YEARS
Resource Materials for Teachers: A Practical Guide
VAL CUMINE, JULIA LEACH
AND GILL STEVENSON

Designed to provide parents and professionals with an insight into the nature and educational implications of autism, particularly as it presents in very young children. Also aims to equip Early Years practitioners and parents with knowledge of a range of intervention strategies to promote learning, social development, communication and appropriate behavior.

NEW

TF5992AT $25.95

CREATING A "WIN-WIN IEP" FOR STUDENTS WITH AUTISM
A How-To Manual for Parents and Educators
BETH FOUSE, PH.D.

This Second Edition, has been written to provide parents and families of students with autism necessary information and skills to meet the challenges of the IEP process. This book takes readers through the child-centered educational process from the stages of initial diagnosis to implementation ad of student's individualized educational programs. Practical suggestions are provided based on federal and state legislative requirements, case law, and the many years of experience the author has in working with the process as a teacher, special education administrator, regional special education consultant and university instructor.

NEW

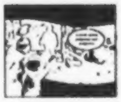
FH7287SE $29.95

A User Guide to the GF/CF Diet for Autism, Asperger Syndrome and AD/HD
LUKE JACKSON; WITH
APPENDICES BY JACQUI JACKSON;
FOREWORD BY MARILYN LE BRETON

Luke Jackson, who is 12 years old and has Asperger Syndrome, tells you everything you need to know, both good and bad. He offers encouragement and practical advice on what to expect when beginning the gluten and casein free diet, how to alleviate any initial discomfort, and how to live with the diet.

NEW

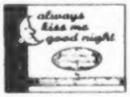
TF0551AS Cost: $17.95



IF THE WORLD WERE BLIND
A Book About Judgement And Prejudice
KAREN GEDIG BURNETT WITH
ILLUSTRATIONS BY LAURIE BARROWS

This fascinatingly unique children's story is relevant to everyone, not just the children it is written for. You will find yourself asking how you view people, and what if, you couldn't view them at all?

CRP3040VI $17.95



ALWAYS KISS ME GOODNIGHT
Instructions on raising the perfect parent
COMPILED BY J. S. SALT

Instructions on raising the perfect parent as seen in the eyes of 147 children. One of the most popular, entertaining, and insightful books a parent will ever find.

RH1090D $7.00

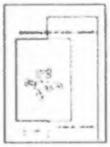
EDUCATION

EFFECTIVE COMMUNICATION
Collaborative Practices For Educators
Strategies for Effective Communication
PATTY LEE, ED.D.

This new revised edition includes 60 strategies and 180 practice activities designed to improve communication and collaboration skills. The activities may be used in any order allowing you and your colleagues to focus on one specific area or work in several areas simultaneously! Covers six (6) critical areas: Developing Expectations; Preparing Ahead; Understanding Perspectives; Listening; Asking Questions and Speaking Clearly.

NEW

PP5261ED $19.95

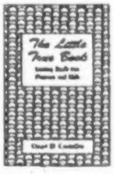


COOPERATIVE LEARNING AND STRATEGIES FOR INCLUSION
Celebrating Diversity In the Classroom
JO ANNE W. PUTNAM

This guide shows educators how to make group learning strategies work in their classrooms. There are chapters written by a distinguished array of professionals who reveal the real educational benefit of a cooperative learning environment.

PB167ED $26.95

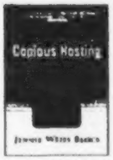
RELIGION



THE LITTLE TRUTH BOOK
Loving Truth for Parents and Kids
ROGER D. CASTERLINE

Do you want a friend for keeps, a real friend? Well Roger D. Casterline will help you get acquainted with one, and his name is Jesus. This book is about relationships, not religion, and if you think you already know Jesus, you can still get to know him even better with the help of this book.

VA9031PA PRICE: $8.95



COPIOUS HOSTING
A Theology of Access for People with Disabilities
JENNIE WEISS BLOCK

This book smartly explores disability and theology in wonderfully contemporary terms. The author confesses not to speak for people with disabilities, yet masterfully examines the breadth and depth of the diverse disability community, and relates this body of knowledge to sometimes conservative theological tenets.

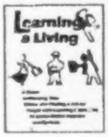
CI3498RE PRICE: $19.95

LEARNING DISABILITIES

EINSTEIN AND ME: TALKING ABOUT LEARNING DISABILITIES
A Video for Parents, Kids & Teachers
JEROME J. SCHULTZ, PH.D.

An upbeat, informative and optimistic video of kids talking openly and honestly, telling about how they found out about their learning disability, policies and people who make life difficult; people and programs that helped them cope; their strengths and talents.

LD100LD $99.00



LEARNING A LIVING
A Guide to Planning Your Career and Finding a Job for People With Learning Disabilities, ADD, and Dyslexia
DALE S. BROWN

A veritable cornucopia of information and tips about the impact of learning disabilities, feedback from others, useful mentor relationships, among other things. Whatever your career interests, this book will help you become successful in realizing your goals.

WB9875LD $18.95

THE EXPERTS SPEAK
Parenting the Child With Learning Disabilities
TERESA A. CITRO

A clear, comprehensive, and direct collection of writings by professionals in the field of learning disabilities in their area of concentration. Whether it is teaching, parenting, or socialization there are stories on it here.

LD200LD (English) $18.99
LD7129LD (Spanish) $18.99

MENTAL RETARDATION

THE BURDEN OF SYMPATHY
How Families Cope with Mental Illness
DAVID A. KARP

This book captures the essence of caring and caregiving for society today. It carefully discusses the emotional and social forces that are at play when caring for a mentally ill person.

NEW

OU3158MR $25.00

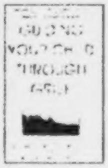
MENTAL RETARDATION IN THE 21ST CENTURY
SPONSORED BY THE ARC OF THE UNITED STATES, EDITED BY: MICHAEL L. WEHMEYER AND JAMES R. PATTON

An interesting and provocative prediction of where technology and society are headed with respect to the treatment of mental retardation in the coming century. Seven Sections covering Family Issues; Education Issues; Employment and Residential Issues; Psychology Issues; Medicine and Health Issues; Life Span Issues and Policy Issues.

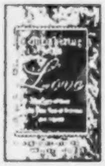
[illegible] $ 44.00

GRIEVING

What on Earth Do You Do When Someone Dies
Trevor Romain
A down to earth explanation for children about death. It offers many ways for children to cope with and understand what is happening.
FS400DE **$7.95**



Guiding Your Child Through Grief
Mary Ann Enswiler, MA, MRS, and James P. Enswiler, MA, M.Ed
This caring and compassionate guide offers expert advice during the . difficult days to help a child grieve the death of a parent or sibling. This book helps readers understand the many secret ways children grieve and offers more insight information, and advice that can help a child heal.
BD0257GR **$13.95**

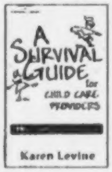


Remembering With Love
Messages of Hope for the First Year of Grieving and Beyond
Elizabeth Levang, PhD. and Sherokee Ilse
An affirming gift for those grieving the loss of a loved one, offering compassion, comfort and guidance with over three hundred short pieces written bv those who have been there.
FP0400E **$11.95**

FOR YOUNG PEOPLE

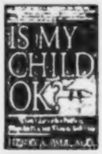
Why Am I Different?
Norma Simon with pictures by Dora Leder
This cute story tackles the idea of difference among children in every way except that of disability. That in itself makes the idea of difference easier to understand, accept, and overcome for any child, especially those that may feel more different that any other child.
AW0746YP **$13.95**

GENERAL



A Survival Guide for Child Care Providers
Tips From the Trenches
Karen Levine
This purposeful book of tips, reflections, and quotes is based upon anecdotal observations of educators with years of resourceful experiences to share with others in the teaching proffession. Serving as a focus for the book are Seven Guiding Principles that are oriented toward early childhood education.
CH0013EN **$13.95**

Neuroimaging
A Window To The Neurological Foundations of Learning and Behavior in Children
G. Reid Lyon, Judith M. Rumsey
Explores the application of anatomical and functional neuroimaging techniques and procedures to the understanding of specific medical conditions and developmental disabilities in children. Includes two chapters covering the basic biological and methodological concepts needed to understand neuroimaging procedures.
PB2568M **$49.95**



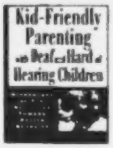
Is My Child OK?
When Behavior Is A Problem, When It's Not, and When to Seek Help
Henry A. Paul, MD
Every parent has asked this question at one time or another. This wise and compassionate guide offers reassuring words for worried parents as well as concrete ways to spot problems between a normal stage of development…and a true problem. This one step reference book tells parents what is normal, what is not, and where to get help.
RN6878CN **$13.00**

Gift Certificates now available for the holidays!

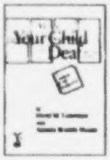
Start the holidays with the "Gift of Knowledge"
Think of your teacher, doctor or friend!
Call 800-535-1910

HEARING IMPAIRED

The Silent Garden
Raising Your Deaf Child Second Edition
Paul W. Ogden
An up to date reference comprising all the bits and pieces of advice, encouragement and hard data that parents might need in order to make decisions that will enable their children to grow into strong, healthy and productive members of society.
GU1030F **$29.95**



Kid-Friendly Parenting With Deaf and Hard of Hearing Children
A Treasury of Fun Activities Toward Better Behavior
Daria Medwid and Denise Chapman Weston
A step-by-step guide offering hundreds of ideas and methods designed to work with children ages 3 to 12 to enhance communication and strengthen relationships in skillful, fun ways.
GH101DF **$24.95**



When Your Child Is Deaf
A Guide for Parents
David M. Luterman with Antonia Brancia Maxon
This must read book provides information for parents about the emotional and educational processes of coming to grips with a hearing impairment in their child. Parents of newly diagnosed hearing impaired children as well as parents of a child with a hearing impairment at any age will find this book helpful.
YP2270HI **$17.95**

VISUALLY IMPAIRED

Children with Visual Impairments
A Parents' Guide
Edited: M. Cay Holbrook, Ph.D.
Designed to help parents get a handle on common types of concerns. Written by a team of professionals and parents, each of whom is an expert on a different aspect of caring for children with visual impairments.
WB17900 **$16.95**

Transition Issues Related to Students with Visual Disabilities
Jane N. Erin and Karen E. Wolffe
An explanation and analysis of the critical areas in the lives of those with visual impairments, such as transportation, academics, employment and recreation.
PE168VI **$12.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: EP, Dept. EP1102, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call 800•535•1910

QTY.	ITEM#	UNIT PRICE	TOTAL

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item
Foreign – $7.00 for 1 item; 75¢ for each additional item

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

These prices are subject to change without notice.

Sub-Total	
NJ Residents 6% Sales Tax	
Shipping	
TOTAL	

Name ______
Address ______
City ______ State ______ Zip ______
Telephone ______ E-Mail ______
I have enclosed my check payable to Exceptional Parent or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover
Account Number: __ __ __ __-__ __ __ __-__ __ __ __-__ __ __ __ Exp. Date ____/____
Signature ______ 1319

Circle #200

familiar faces

PATRICK

JOSIAH

Patrick H. Gregg,15, and younger brother **Josiah Raymond Gregg**, 6, were both born with a rare genetic disorder called Neonatal Adrenaleukodystrophy. Patrick is blind, partially deaf and is severely and profoundly developmentally delayed. Josiah has a trache and had a liver transplant and partial bone marrow transplant when he was two years old. Patrick enjoys swimming and Josiah loves horses and enters a yearly reading contest that is sponsored by the Congress Library for the Blind. Their parents, Ron and Deenna Gregg of Clinton, Iowa, love them both very much.

AUSTIN

Austin Jeremiah Scudder is 22 months old and has Cerebral Palsy. Austin is a happy little boy who loves his parents and enjoys Elmo, Baby Einstine videos, and swimming at the YMCA. His grandmother Joy says that he's a sweet, loveable and sassy child, and a "gift to our family."

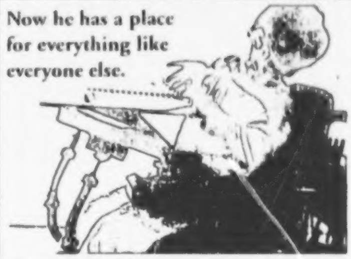
LILY

Lilly Isabella Lutterman, 2, is "a blessing," according to her mother Debbie. She was diagnosed at birth with Down syndrome, had heart surgery at four months and had a pacemaker put in ten days later. Now she is able to walk part-time, and has made life complete for the rest of her family, including her parents Bill and Debbie as well as her five siblings.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (EXCEPTIONAL PARENT), 65 E. Route 4, River Edge, NJ 07661. (Please do not send "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

PRODUCT SHOWCASE

Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

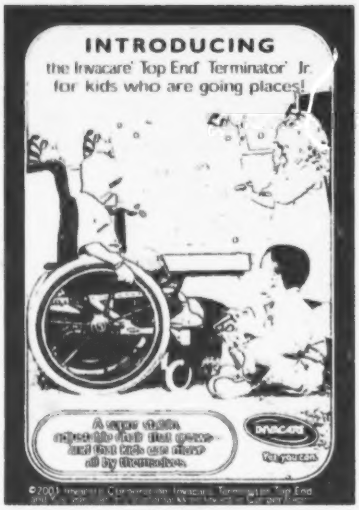


Now he has a place for everything like everyone else.

It's unique ball-joint movements and sturdy support put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, and pencils. And when it's time for transfers, the entire desktop swings down to the side.

1-800-4 MYDESC
www.mydesc.com
Santa Clara, CA 95056

Circle #1



INTRODUCING
the Invacare' Top End' Terminator' Jr. for kids who are going places!
INVACARE
Yes, you can.

Circle #2

freedom
what is your definition?
call us today!

1.800.661.9915
www.freedomconcepts.com

Circle #3

Diaper Doublers™

Diaper Doublers inserts that make cloth or disposable diapers more efficient, pulling moisture away from a child's tender skin.

- **Trim & Comfortable**
- **Overnight Protection**
- **Absorbency without Bulk**
- **Latex-Free for Sensitive Skin**

www.DiaperDoubler.com
1-800-335-4434
Toll-Free Phone Orders
"The Drier Way to Diaper"™

Circle #4

Ability Camp Inc.
Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

MARKETPLACE

ACCESSIBLE TRAVEL

AFFORDABLE WHEELCHAIR VAN RENTALS
Orlando-Miami-Fort Lauderdale by Medical Travel Inc. Disney World Accessible Roll in Shower Villa's for RENT. Thinking of buying a Van— Price us Last. www.medicaltravel.org
1-800-778-7953

VAN CONVERSION DEALERS

MASSACHUSETTS

MOTION AUTOMOTIVE SPECIALTY
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals— Day, Week or Month.

MONITORING SYSTEM

CARE ELECTRONICS INC.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price.
Call for FREE CATALOG

BEACH WHEELCHAIR

Affordable Independence in the Great Outdoors!

The Features Make All the Difference!

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure

TOYS AND HOBBIES

TFH (USA) LTD
4537 6B Gibsonia RD.
Gibsonia, PA 15044
(800) 467-6222
www.tfhusa.com
e-mail: info@tfhusa.com
Fun products for recreation and education of special needs children.
Request a FREE catalog.

INCONTINENCE

ARC HOME HEALTH PRODUCTS
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so.Contact us to find out. Many other brands, styles & sizes available.
NY State Medicaid Provider.
Resource information:
www.medmarket.com
e-mail: info@archhp.com

Ask about our Youth/Small Brief sample pack.
Only $9.95

HDIS

FREE CATALOG
Call Today!
1-800-2MY-HOME®
(1-800-269-4663)

CLOTHING

David's Collection

Fashionable & durable vinyl backed terry cloth **BIBS** made to order
Choice of pattern & style

Sm. $13.00
Md. $15.00
Lg. $17.00
plus s&h $ 3.50

NEW
Vinyl Backed Tie Bandanas
$6.50 plus s&h

CALL DAVID'S MOM
For more info — ordering
410-668-0068

Visit: www.DavidsCollection.com

FREE INFORMATION RESOURCE

TURTLE BOOKS

JASON & NORDIC
Lots of upbeat stories, neat illustrations, for kids with disabilities & their friends.
Tackles real-life issues.
Jason & Nordic
P.O. Box 441Holidaysburg, PA 16648 (814) 696-2920
Fax (814) 696-4250
www.jasonandnordic.com
FREE CATALOG

EDUCATIONAL MATERIALS

DIFFERENT ROADS TO LEARNING
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

ATTAINMENT COMPANY
P.O. Box 930160
Verona, WI 53593-0160
800-327-4269
Special Products for Special Needs. Reinforce learning at home with the same materials that school districts use, at reduced prices! At AttainmentFamily.com we have a wide variety of products to help your child succeed at school, home and work. Visit us at www.attainmentfamily.com.

Special-Needs Collection

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on...

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

EQUIPMENT DEALERS

American
Discount Medical
Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!
Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands—Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @
www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

SENSORY INTEGRATION

Sensory Integration Equipment

Providing custom-made weighted items. Sturdy, affordable, comfortable, non-clinical appearance.

Weight Vests
Weight Blankets

Angel Moon Creations
503-589-9552
www.angel-moon-creations.com
An OT Owned Company

SWITCHES

BUBBLES™ SWITCHES — for those who have difficulty using ordinary switches. Touch-sensitive, or it can be set so the hand only needs to pass near the switch! Convenient dome shape.

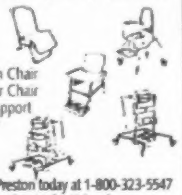
MINIMAL MOTION™ SPLINT SWITCH KITS — touch-sensitive switch pads to mount directly on hand splints.

EQUAL ACCESS COMPUTER TECHNOLOGY, INC. 978-466-9191
222 Grant Way, Lancaster, MA 01523
Email: eact@world.std.com

SEATING & POSITIONING

DESIGNED WITH CHILDREN IN MIND
Leckey's full line of products have been re-designed to make your child's standing, sitting or toileting experience easier and more enjoyable. Leckey products feature lighter mobile bases, more adjustable components, peer level positioning, child friendly positioning straps and playful colors.

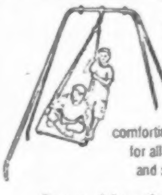
- Freestander
- Totstander
- Easy Seat
- Advance Bath Chair
- Toilet/Shower Chair
- Basic Bath Support
- Pronestander



Call Sammons Preston today at 1-800-323-5547 for a complete Leckey® brochure.

SWINGS

Portable Swing Stand



Therapy Swings

Safe, strong comforting & affordable for all your swinging and spinning needs

For more information contact
Take-A-Swing LLC
602-451-5544 • www.takeaswing.com

4TALK4

The 4talk4 is an augmentative communication aid with four levels of pre-recorded messages and four push button switches. It features speech output, volume control, and plastic pockets for pictures that represent each message. The 4talk4 also has ports for external switches and for battery-operated devices.

Inclusive TLC, Inc, 315 Wootton Street, Boonton, NJ 07005; 800-462-0930, 973-331-9898, 973-331-9849 fax; E-mail: info@inclusiveTLC.com;
URL Web Site: http://www.inclusiveTLC.com

LECKEY TOT STANDER

The Leckey Tot Stander is a standing aid designed for children with mild to moderate mobility disabilities. The Tot Stander comes with chest band, knee supports, footplate and sandals. Other features include a padded pelvic plate and pelvic band to promote up right posture. To increase postural support the optional knee spacers and high back strap accessory can be added. The Leckey Tot Stander also has a low baseboard that allows for quick and easy transfers. This standing frame accommodates children sixteen months to four years of age.

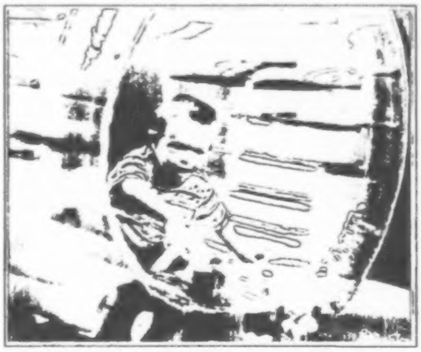
Sammons Preston, Inc., An Ability One Company, P O Box 5071, Bolingbrook, IL 60440-5071; 800-323-5547, 800-547-4333 Fax; E-mail: sp@sammonspreston.com;
URL Web Site: http://www.sammonspreston.com

WOMBAT HIGHLOW POSITIONING CHAIR

The Wombat HighLow positioning chair is designed for children one to twelve years old with mild to moderate levels of physical disabilities. It comes with seat belt, adjustable footrest, and locking casters. The Wombat is available in a Basic model and an Upgrade model. The Basic model features manual seat height adjustments and the Upgrade model provides either gas spring or power lift seat height adjustments. The Wombat HighLow positioning chair also has a tilt-in-space feature, which adjusts from -20 degrees to +20 degrees.

Snug Seat, Inc, PO Box 1739, Matthews, NC 28106-1739; 704-882-0668, 800-336-SNUG, 704-882-0751 Fax; E-mail: info@snugseat.com;
URL Web Site: http://www.snugseat.com

SENSATRAK



SensaTrak is a crawling prompter that stimulates vestibular, visual, auditory and motor senses. This clear vinyl power inflated tube features two side columns and twenty-six activity chambers in the center. The columns are filled with yellow, green, blue, purple, red, and orange flowing balls. The chambers are divided by number, letter, and color.

Abilitations, One Sportime Way, Atlanta, GA 30340-1402; 800-850-8602, 800-845-1535 Fax; E-mail: orders@sportime.com;
URL Web Site: http://www.abilitations.com

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

1323

"My Hero"

by Nicole Goldstein

I have a brother with Down syndrome. He teaches me things like to be patient and take your time. He also teaches me to be happy with what I have and with who I am. Sometimes the most unlikely people can teach you the most important lessons in life.

His name is Jonah but everyone calls him JJ and he's six years old. JJ's the one that taught me all about Down syndrome by the way I watch him grow, learn new things and act. My brother is one of the cutest six-year-olds I have ever seen. He's a model and was in a commercial and two magazines for Toys R Us.

My friends never have a problem with the fact that I have a brother with Down syndrome. They think JJ is extremely cute and funny. He runs, jumps and plays like any other six-year-olds around. JJ takes gymnastic lessons and he's very good at it. He can do a cartwheel and even a handstand.

I once went to a program in JJ's school with my family. We met his teachers and friends. There we learned sign language because when JJ was younger and he couldn't talk he used sign language to tell us what he wanted. That was a fun day!

I worry so much about JJ and always look out for him. One time he got lost in a hotel in the Bahamas. JJ and I woke up early one morning when everyone was asleep. Without noticing JJ walked out of the hotel room. He decided to take a little ride on the elevator. He rode all the way up to the fifteenth floor. A family found JJ in the elevator alone on their way down to breakfast. They called security and we couldn't find him for at least an hour. It scared me so much because I love him.

I have some advice for brothers and sisters with siblings with special needs. I was five years old when JJ was born. Before I knew what Down syndrome was I told my mother that I wished I had Down syndrome because JJ was getting a lot of attention. My mother told me that he gets a lot of attention because he learns a lot from everyone around him and I want to help him. As I got older I understood that my parents love me just as much as they love JJ and I don't need the same kind of attention that he does.

JJ and Nicole Goldstein

I want to say how much I love JJ and I love him just the way he is. But I hope that one day he will be able to talk better and I know that he will because he's very smart and there are so many people to help him get there. No matter what, JJ is my hero. EP

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number and e-mail address! ***Now on the Web!*** We now include **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.

"in my mind, i cannot hide my joy."

What makes a happy person happy? Is it the capacity to learn, love, laugh? The gift to embrace life? Is it a sense of purpose? To be part of the solution, not the problem? Or perhaps the ability to take great joy in giving and demonstrate even greater humility in receiving? At Kennedy Krieger, we believe it is all this and more. We care for and treat children with developmental disorders such as cerebral palsy, autism, Down syndrome, and others. Working together, we give each other a great sense of purpose and a daily reason to smile. We learn as much from our young patients and students as they learn from us and we are inspired by their courage. In return, we dedicate ourselves to helping and healing them, so that each child may experience the full joy of life. And that, makes us all very happy.

Every child is born with great potential. Shouldn't every child have the chance to achieve it?

Kennedy Krieger Institute

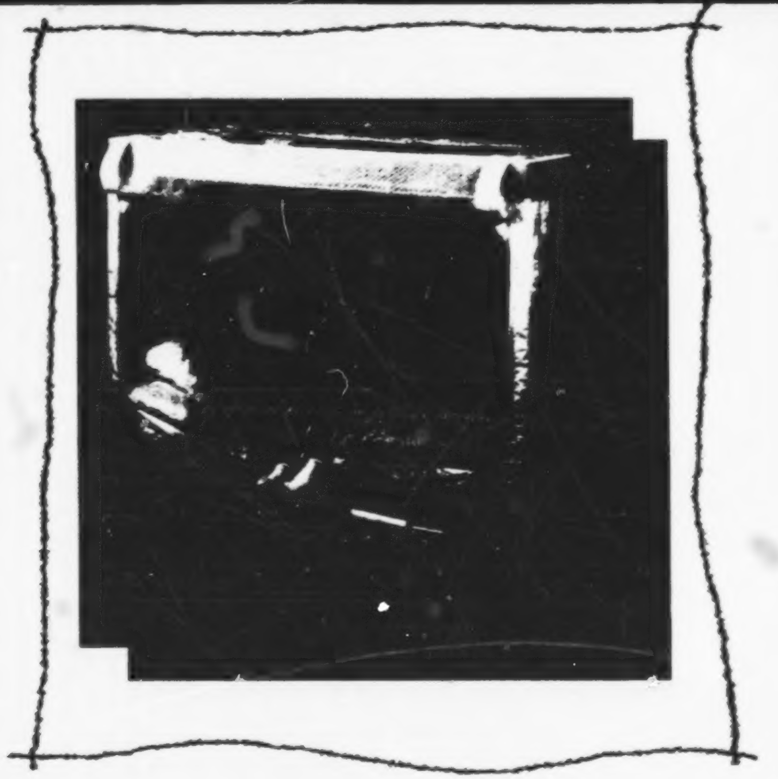
Research. Treatment. Education.

www.kennedykrieger.org Our toll-free referral line: 1.888.554.2080

Circle #44 or visit www.eparent.com/adinfo

A Better Bedtime Story

The Vail Enclosed Bed



Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for your child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt. Plus, we provide assistance in obtaining insurance approval.

Available from home health-care products dealers, or direct from the manufacturer.

For a FREE catalog, call: 1-800-235-VAIL

Vail Meadows Therapeutic Riding Center

Corporate Sponsor of Vail Meadows Therapeutic Riding Center

Happy challenges for challenged riders.

Ask about Our Decorator Accessories.

"Allison had trouble falling asleep due to neurological damage. But the Vail bed has conditioned her to fall asleep. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep."

Sheri Wittmer
Sandusky, Ohio

1326

Circle #59 or visit www.eparent.com/adinfo

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

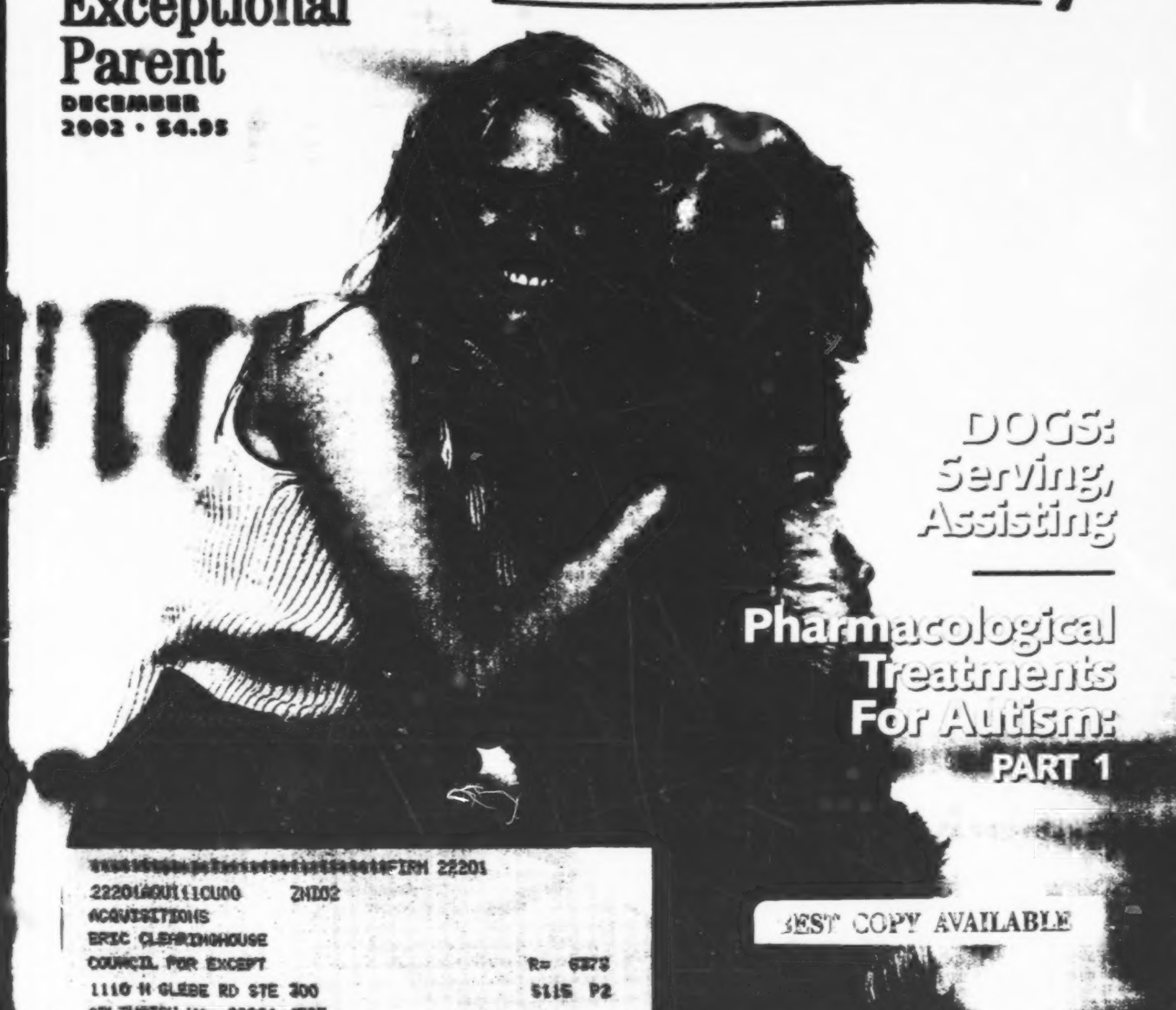
VISA MasterCard

Information and Support for the Special Needs Community
PARENTS • FAMILIES • PHYSICIANS • PROFESSIONALS

EP
Exceptional Parent

DECEMBER
2002 • $4.95

Family & Community



DOGS: Serving, Assisting

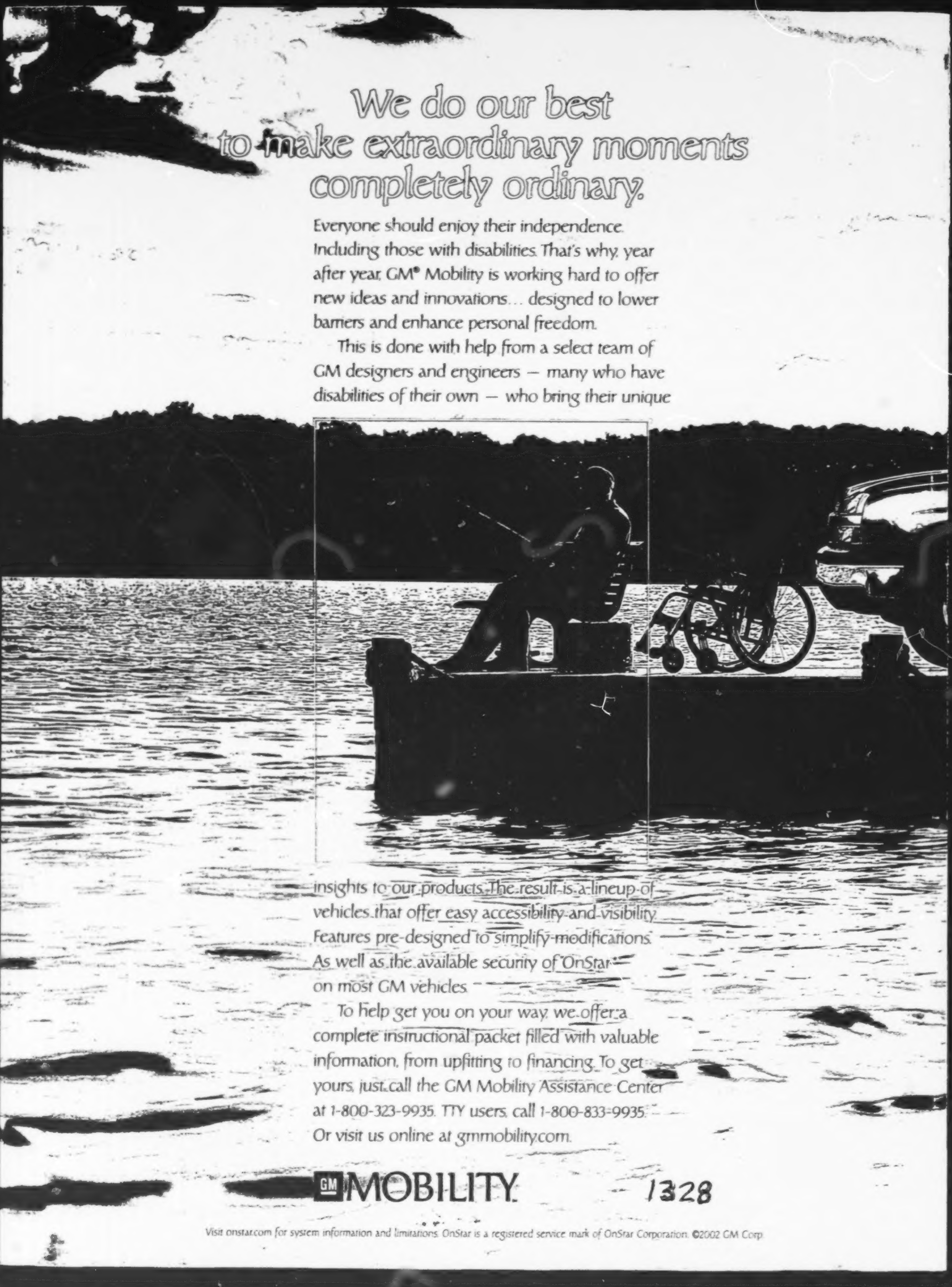
Pharmacological Treatments For Autism: PART 1

[illegible]FIRM 22201
22201AQU111CU00 ZHD02
ACQUISITIONS
ERIC CLEARINGHOUSE
COUNCIL FOR EXCEPT R= 6873
1110 N GLEBE RD STE 300 5115 P2
ARLINGTON VA 22201-4795

BEST COPY AVAILABLE

www.eparent.com

1327



We do our best to make extraordinary moments completely ordinary.

Everyone should enjoy their independence. Including those with disabilities. That's why, year after year, GM® Mobility is working hard to offer new ideas and innovations… designed to lower barriers and enhance personal freedom.

This is done with help from a select team of GM designers and engineers — many who have disabilities of their own — who bring their unique insights to our products. The result is a lineup of vehicles that offer easy accessibility and visibility. Features pre-designed to simplify modifications. As well as the available security of OnStar on most GM vehicles.

To help get you on your way, we offer a complete instructional packet filled with valuable information, from upfitting to financing. To get yours, just call the GM Mobility Assistance Center at 1-800-323-9935. TTY users, call 1-800-833-9935. Or visit us online at gmmobility.com.

GM MOBILITY

Visit onstar.com for system information and limitations. OnStar is a registered service mark of OnStar Corporation. ©2002 GM Corp.

CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

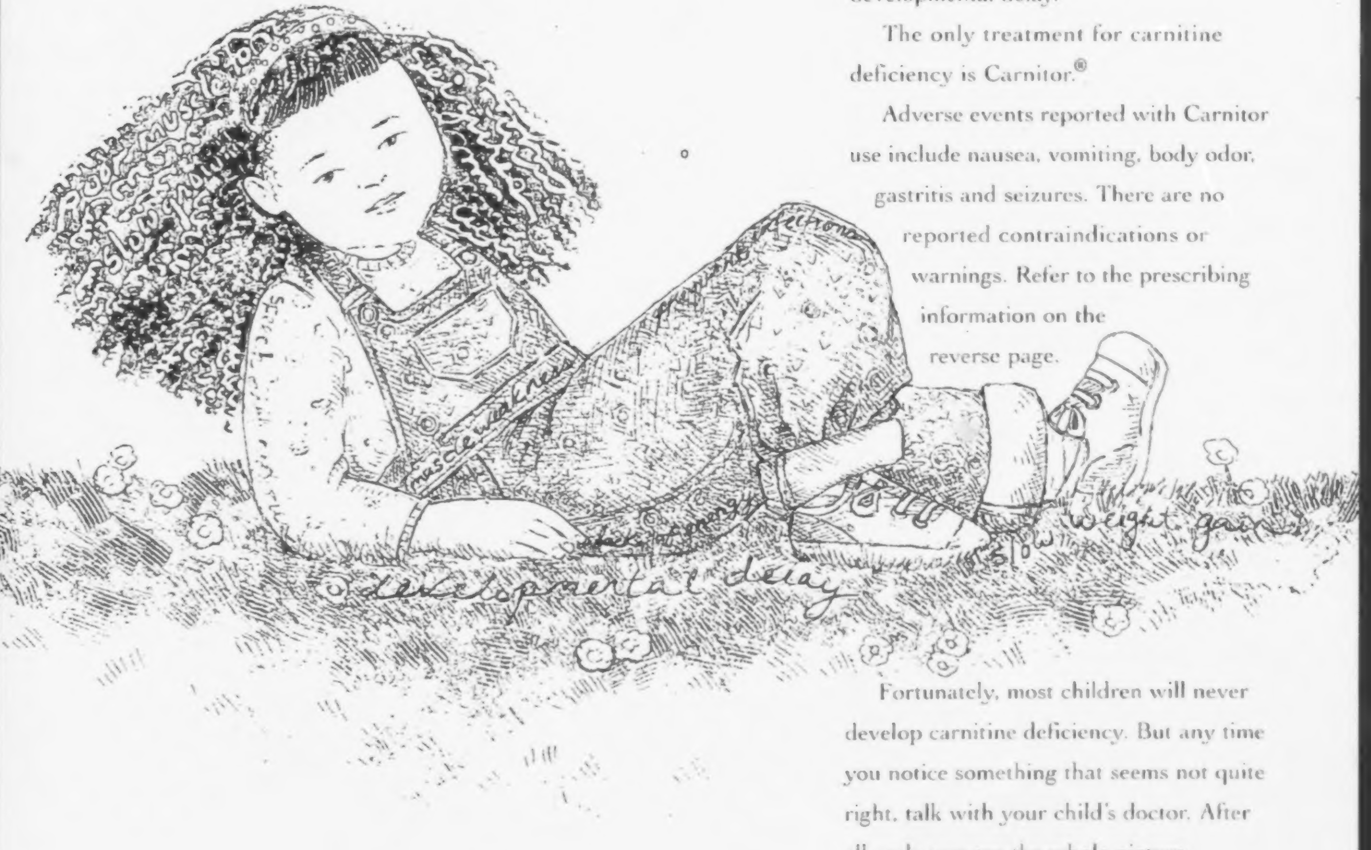
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

©2000 Sigma-Tau Pharmaceuticals, Inc. All rights reserved. PA-10

Circle #44 or visit www.eparent.com/adinfo

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

σ sigma-tau
PHARMACEUTICALS, INC.

GAITHERSBURG, MD 20877

TEL: (800) 447-0169
FAX: (301) 948-3194
E-MAIL: info@sigmatau.com
WEB: www.sigmatau.com

OBS-2
2/00

All children should be seen. And heard.

With free Verizon assistive equipment, the lines of communication are open to children with disabilities.

If you're the parent of a child with a disability, you know that talking on the phone is just as important to him as it is to every other child. Which is why, if your child qualifies, you should apply for free assistive equipment from Verizon. To qualify, your child must be under 18 and have a certified disability that hinders him (or her) from using the phone, and receive SSI disability benefits.

The equipment covers the range from TTYs and volume-amplified telephones to light signalers, loud tone ringers, and large-number and hands-free telephones.

As you already know, every child has something to say. Now yours can say it on the phone much easier than before. **For recorded information about the program or to request an application, call 1 800 882-6828 (V) 1 800 299-2640 (TTY)**

This is a limited time offer and applies only to New York State Verizon customers or their dependents living in the same household, for as long as our supply of this equipment lasts.

verizon

Circle #49 or visit www.eparent.com/adinfo

contents

DECEMBER 2002 • VOLUME 32, ISSUE 12

Family & Community

28 **Back Toward Normal: How our Family Recovered After Alison was Born**
By Genevieve Anton
How one family remained the active and strong group they had been before the birth of a child with disabilities.

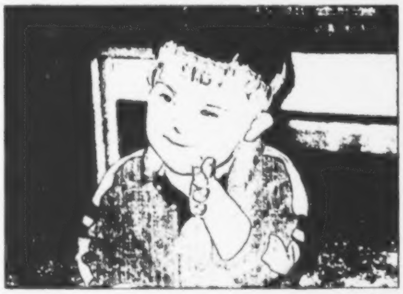
31

34 **Families Tell Us: What Makes Families Strong**
By Sally Darley, LMSW; Jim Porter, MSW, LISW; John Werner, LMSW; Susan Eberly
The results of surveys taken on parents of children with special needs and how families cope with situations and remain strong.

37 **More Than Just Loving Pets: Dogs Improve Quality of Life**
By Laura Apel
Assistance dogs and the impact that they have on the lives and families of those with disabilities.

42 **Family Dynamics in the Treatment of Tourette Syndrome**
By Lynne Rosen, CSW
A psychotherapist discusses her experiences and treatments with a young girl who has Tourette Syndrome and her mother.

38



45

45 **Signing for Success**
By Abbey Woodard
One mother's experience with sign language as a great method of communication with a child who cannot express himself verbally.

47 **Early Intervention Services: A Family-Professional Partnership**
By Carolyn Cantu, MS, OTR
How Early Intervention Programs can help with the expectations, services, costs and treatment options that face children with disabilities and their families.

FEATURES

51 **A Pediatrician's Treatment for Her Daughter**
By Jo Feingold, MD
The second of a two-part story written by a pediatrician and mother of five who used HBOT for her daughter who has Cerebral Palsy.

53 **Wraparound Mental Health Services**
By Stephen J. Bugaj, EdD, Randall L. Manning and Renee Brunner
Common questions and answers about the mental health services in your home, school and community.

56

56 **A Parent's Determination and a Pre-K Dream Realized**
By Sherri H. Epstein and Ann G. Bessell, PhD
A mother's story of the battle she was forced to fight to ensure an inclusive and appropriate education for her daughter.

64 **Health Care Institution of the Month: The Valley Hospital**
The hospital is recognized for its excellent programs, including universal newborn screening and their Center for Child Development.

SPOLIGHT ON AUTISM

66 **Pharmacological Treatment Options for Autism, Part 1**
By C.T. Gordon, III, MD
A discussion of safe and effective medications which can be applied to the treatment of autism.

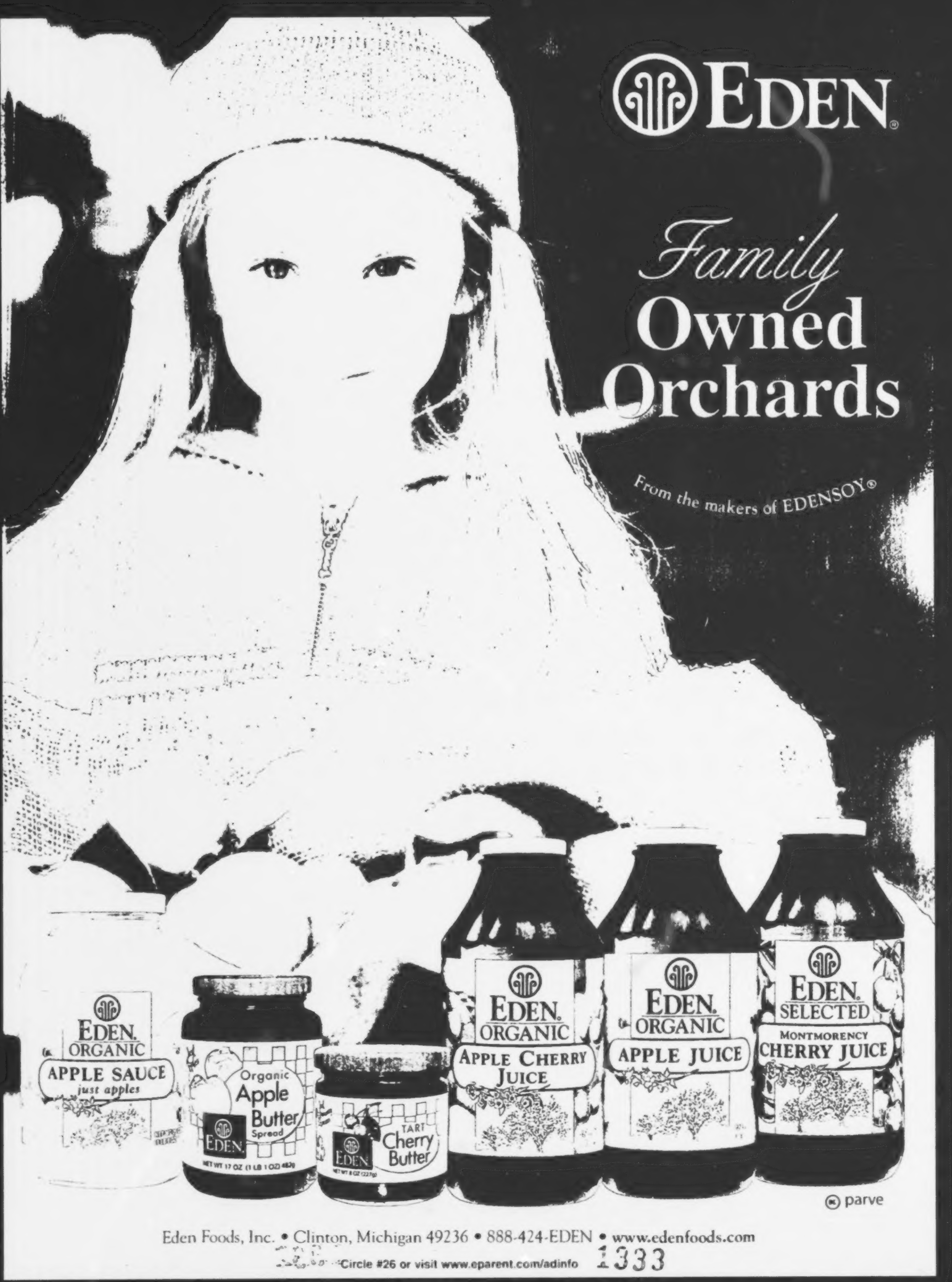
82 **Oral Sensitivity, Dental Health and Prevention**
By Lee Barks, RN, MN, ARNP, FAAMR and Debbie Lord, MA, CCC, SLP/L, FAAMR
The third of a series of articles written by the AAMR (American Association on Mental Retardation).

78

ON OUR COVER: The stars of Pax TV's new hit show "Sue Thomas: F.B.Eye." Deanne Bray, who portrays the real life deaf Federal Agent, and Jesse as her hearing dog, Levi.

EP
Exceptional Parent

Spotlight on Autism partially supported by an educational grant from Janssen Pharmaceutica, L.P.



EDEN®
Family Owned Orchards
From the makers of EDENSOY®
EDEN ORGANIC APPLE SAUCE just apples
Organic Apple Butter Spread EDEN NET WT 17 OZ (1 LB 1 OZ) 482g
TART Cherry Butter EDEN NET WT 8 OZ (227g)
EDEN ORGANIC APPLE CHERRY JUICE
EDEN ORGANIC APPLE JUICE
EDEN SELECTED MONTMORENCY CHERRY JUICE
Ⓚ parve

Eden Foods, Inc. • Clinton, Michigan 49236 • 888-424-EDEN • www.edenfoods.com
Circle #26 or visit www.eparent.com/adinfo

contents

DEPARTMENTS

13 **Editor's Desk**

14 **Search and Respond**

22 **Letters to the Editor**

24 **What's Happening**

61 **Org. Spotlight**
United Brachial Plexus Network, Inc.

71 **Further Reading**
By Megan Henninger

72 **Research Reflections**
This Holiday Season's Best Buy: OPTIMISM
By Jan Blacher, PhD

78 **Fashion Corner**
By Lori Ostrover

80 **In Depth**
- Risk Genes for ADHD
- Rise in Autism Attracting Attention

88 **New Products**

91 **Familiar Faces**

92 **Children's Page**
My Favorite Cousin
By Andrea Tocci

92

Exceptional Parent (ISSN 0046-9157) is published monthly 11 times per year plus special January Issue by Psy-Ed Corp., dba *Exceptional Parent Magazine*, 65 East Route 4, River Edge, NJ 07661. **Internet address: http://www.eparent.com.** All rights reserved. Copyright ©2002 by Psy-Ed Corp. *Exceptional Parent®* is a registered trademark of the Psy-Ed Corp. **Postmaster:** Please send address changes to: *Exceptional Parent,* P.O. Box 2078, Marion, OH 43306-2178. Periodical postage paid at Boston, Mass. and additional mailing offices (USPS 557-810). Basic annual subscription rate is $39.95 per year. Annual subscription rate for Canada is $54.95 (U.S. funds only); all other foreign countries $57.95 (U.S. funds only). **Subscriber Service:** Direct all inquiries & address changes to: *Exceptional Parent,* P.O. Box 2078, Marion, OH 43306-2178. **Customer Service/New Orders:** E-mail: EPAR@kable.com or call toll free: (877) 372-7368 and ask for Customer Service, *Exceptional Parent.* Back issues incur a charge of $6.50 each and depend upon availability, call(877) 372-7368. Agreement #4006 0754. RBW Graphics, 2049 Twentieth St. East, Owen Sound, Ontario, CAN N4K 5R2

Exceptional Parent neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed health professional before use and purchase.

NOTE FROM THE EDITOR-IN-CHIEF:
EP advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative nomenclature.

—Rick Rader, MD

EP EDITORIAL ADVISORY BOARD

LAUREN AGORATUS, Parent, NJ state and MCH Region II (NJ, NY, PR, VI) Coordinator for Family Voices, NJ CCAN (Caregiver Community Action Network), National Family Caregivers Association, Mercerville, NJ

MARK L. BATSHAW, MD, Prof. and Chairman, Dept. of Pediatrics, The George Washington Univ. Medical Center, Washington, DC

ADRIENNE FALK BERGEN, PT, Seating and Wheeled Mobility Specialist, National Seating and Mobility, Westbury, NY

T. BERRY BRAZELTON, MD, Clinical Prof. Emeritus of Pediatrics, Harvard Medical School, Boston, MA

ALLEN C. CROCKER, MD, Director, Developmental Evaluation Center, Children's Hospital, Boston, MA

MAHLON DELONG, MD, Chair, Dept. of Neurology, Emory Univ., Atlanta, GA

MURRAY FEINGOLD, MD, Physician-in-Chief, National Birth Defects Center, Waltham, MA

LAURA FITZELL, MSW, Social Worker, Valley Infant Developmental Service, Springfield, MA

CHRIS FEUDTNER, MD, PhD, Pediatrician, Pediatric Care Center, and Department of Pediatrics, University of Washington, Seattle, WA

EMMETT FRANCOEUR, MDCM, FRCPC, Past President, Canadian Paediatric Society, Ottawa, ON, CAN

ARNO H. FRIED, MD, FACS, Director, Pediatric Neuroscience Institute, Hackensack University Medical Center, Hackensack, NJ

KAREN GAFFNEY, Advocate, Speaker, President of the Karen Gaffney Foundation, Portland, OR

STANLEY I. GREENSPAN, MD, Clinical Prof. of Psychiatry and Behavioral Pediatrics, The George Washington Univ. Medical School, Washington, DC

JOAN EARLE HAHN, DNSc, RN, CS, CDDN, Assistant Adjunct Prof., Univ. of California, Los Angeles School of Nursing; Past President, Developmental Disabilities Nurses Association

MICHAEL D. SUSSMAN, MD, President, American Academy of Cerebral Palsy and Developmental Medicine, Shriner's Hospital for Children, Portland, OR

DAVID HIRSCH, MD, Phoenix Pediatrics, Phoenix, AZ

CHRIS P. JOHNSON, MEd, MD, FAAP Associate Prof. Pediatrics, Univ. of Texas Health Science Center, San Antonio, TX

JOHN H. MENKES, MD, Director of Pediatric Neurology, Cedars Sinai Medical Center. Prof. Emeritus of Neurology and Pediatrics Univ. of California, Los Angeles, CA

FRANK J. MURPHY, President and CEO, EP Foundation for Education, Atlanta, GA

EDWARD NEWMAN, PhD, Prof., Temple Univ. School of Social Administration, Philadelphia, PA

BETTY PENDLER, MS, Parent, Member, New York State Developmental Disabilities Planning Council, New York, NY

STEVEN P. PERLMAN, DDS, MScD, Associate Clinical Professor, Boston University School of Dentistry, Boston, MA

HARVEY PRESSMAN, President, Corporation for Opportunity Expansion, Newton, MA

SIEGFRIED M. PUESCHEL, MD, Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

ESTHER SCHLEIFER, MSW, Clinical Social Worker, Boston, MA

HOWARD SHANE, PhD, Director, Communications Enhancement Center, Children's Hospital, Boston, MA

ARTHUR SHAPIRO, EdD, Professor of Special Education, Kean University, Union, NJ

HELEN TAGER-FLUSBERG, PhD, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, MD, Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, PhD, Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

HAROLD TURNER, D.D.S., Editor Emeritus, Oral Health

JO WALDRON, Parent, Disabled American for the Nation, Chief Operations Officer, New World Sounds, Inc., Fort Collins, CO

Quality for life

The Bugsy walker's maximum adjustability and solid, lightweight construction provide safety, convenience, and functionality like no other.

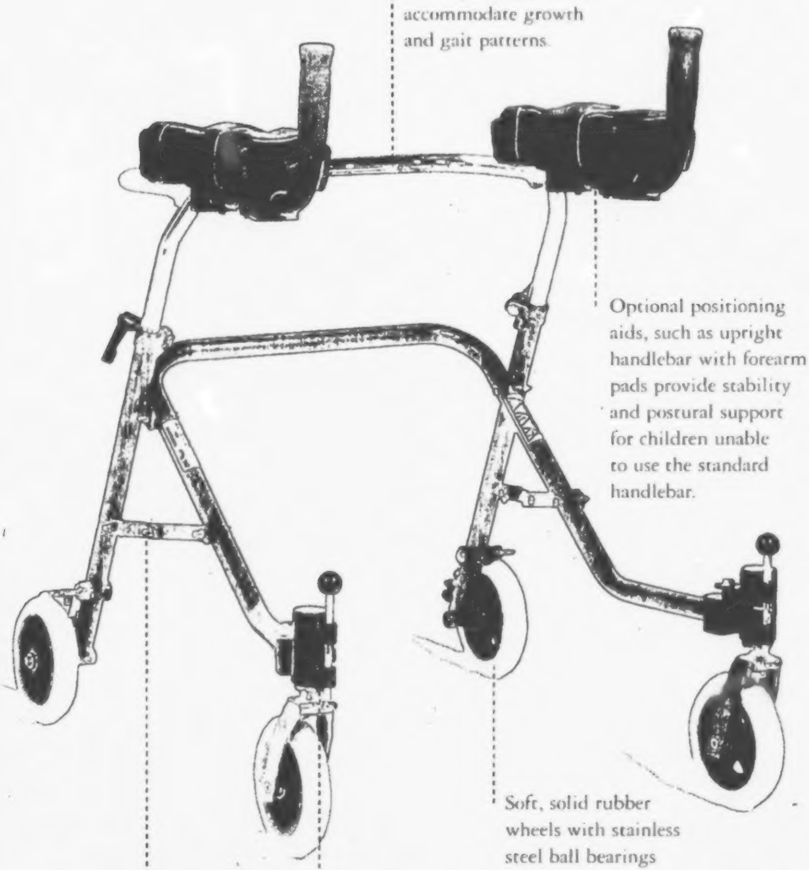
The Bugsy's highly adjustable design encourages active postural control during standing and walking, while also promoting a more natural movement. Unlike other walkers, Bugsy's solid rubber wheels feature stainless steel ball bearings for smooth, easy maneuverability. The anti-reverse wheel design prevents inadvertent backward rolling for safety. Lightweight construction and a quick fold-up feature provide easy handling and storing.

Contact your Otto Bock Sales Representative (U.S. 1-800-328-4058 or Canada 1-800-665-3327) to see the Bugsy pediatric postural walker firsthand.

Otto Bock
HEALTH CARE

www.ottobockus.com
www.ottobockcanada.com

CONTROL



Handlebars are height and depth adjustable to accommodate growth and gait patterns.

Optional positioning aids, such as upright handlebar with forearm pads provide stability and postural support for children unable to use the standard handlebar.

Lightweight and easily folded for added convenience.

Optional swivel wheel locks and rear friction brakes provide directional control and extra safety.

Soft, solid rubber wheels with stainless steel ball bearings provide easy rolling and maneuverability even under heavy pressure.

Optional hip pads and seat

Optional back support and handle grips with wooden stops

© 2002 Otto Bock Health Care U.S., Inc. Cloud is a trademark of Otto Bock Health Care U.S., Inc. 20020405-4

Circle #41 or visit www.eparent.com/adinfo

A place of *their* own...

A place for encouragement...

A place for friends...

A place for growth...

A place for independence...

A place for life!

- Paid Vocational Training and Job Placement
- Daily Classes: Remedial Education, Arts, Recreation, Living/Life Skills
- Cottages and Apartments
- Case Management/ Health Services
- Degenerative and Aging Service Options
- Nursing Home

Annandale
VILLAGE

Serving Adults having MR/DD

Visit us on the Web:
www.annandale.org

3500 Annandale Lane
Suwanee, Georgia 30024
Tel. 770.945-8381 • Fax 770.945.8693

Annandale Village is certified by the IRS as a private, 501(c)(3) nonprofit corporation.
Georgia Permit # 067-03-001-01
Charitable Registration # 01-911713

Circle #17 or visit www.eparent.com/adinfo

EP

EXCEPTIONAL PARENT MAGAZINE

Information and Support for the Special Needs Community

EDITOR-IN-CHIEF	RICK RADER, MD
CONSULTING MANAGING EDITOR	DONALD P. MAZZELLA
ASSISTANT MANAGING EDITOR	LAURA APEL
MEDICAL EDITOR	FERN R. POTVIN
ASSISTANT EDITOR	LORI OSTROVER
ASSISTANT EDITOR	ARNOLD KIM
ASSISTANT EDITOR	JULIA STEELE
BOOK EDITOR	MEGAN HENNINGER
INFORMATION SYSTEMS COORDINATOR	DENNIS DUSEVIC
RESEARCH ASSISTANT	SUSAN JENKINS
GRAPHIC CONSULTANT	DENNIS WILKES

PRESIDENT, CEO & PUBLISHER	Joseph M. Valenzano, Jr.
VP BUSINESS DEVELOPMENT & INTERNET PROJECTS	Vanessa B. Ira
CONTRIBUTING EDITOR & VP ORGANIZATION RELATIONS	Bridget M. Lyne
CHIEF FINANCIAL OFFICER	Dolores A. Kinley
AD TRAFFIC MANAGER	Kendra Kelly
SALES COORDINATOR	Doris DeFina
RECEPTIONIST/PUBLIC RELATIONS COORDINATOR	Robyn Sager
ART DIRECTION, DESIGN	Publishers Design Group, Inc. ✉annpdg@aol.com
PRODUCTION MANAGER	Michael Longobardi
EP LIBRARY	Ron Richards (800) 535-1910 ✉eplibrary@aol.com
WEBMASTER	Ken Fleischer, Dynamic Media Works ✉webmaster@eparent.com

SALES REPRESENTATIVES AND TERRITORIES

Vanessa B. Ira
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 ext. 209
✉ vira@eparent.com
CANADA

Annabelle & Gabe Jacobson
The Lyon Group
806 Lawler Aveenue
Wilmette, IL 60091
(847) 256-6850
✉ bellyon@megsinet.net
MI, WI, IA, IL, IN

Bill Joubert
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ bjoubert@superlink.net
MT, ND, MN, SD, WY, NE, KS, OK, TX

Jared Adams
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ jadams@eparent.com
DE, MD, DC, WV, VA, NC, SC, GA, FL, KY, TN, AL, MS, LA, AR, MO

Matt Valenzano
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 x211
✉ mattvalenzano@eparent.com
ME, VT, NH, MA, RI, CT, NY

Brian Regan
65 East Route 4
River Edge, NJ 07661
(201) 489-4111
✉ brianregan@sprintmail.com
PHARMACEUTICALS

Larry Battistello
Marketing Plus
3155 East Ramon, Unit #203
Palm Springs, CA 92264
(760) 320-8797
Fax: (760) 320-9728
✉ seeme4ads@aol.com
TERRITORY: WA, OR, ID, NV, CA, UT, CO, AZ, NM

Barbara Nastro
65 East Route 4
River Edge, NJ 07661
(908) 534-6366
(908) 534-6941-fax
✉ nastro@blast.net
NJ, PA, SCHOOLS, CAMPS & RESIDENCES, MARKETPLACE

COLOR SEPARATION/FILM PREPARATION
AGT7 Carlstadt, NJ 07072

LIST RENTALS
GRS
Mktg Services Inc.
187 Billardvale Street
Wilmington, MA 01887
Attention: Mark Hammar
978-661-8126
mhammar@mktgservices.com

PUBLISHING & EDITORIAL OFFICE
65 East Route 4
River Edge, NJ 07661
(201) 489-4111 • Fax (201) 489-0074
Advertising sales: (800) E-PARENT

SUBSCRIBER SERVICE:
EXCEPTIONAL PARENT
P.O. Box 2078, Marion, OH 43306-2178.

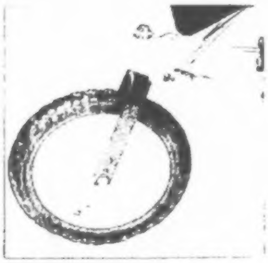
CUSTOMER SERVICE/NEW ORDERS:
E-mail: EPAR@kable.com
(877) 372-7368 (toll free)

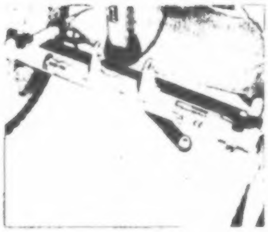
EXCEPTIONAL PARENT magazine was founded in 1971 by Maxwell J. Schleifer, PhD

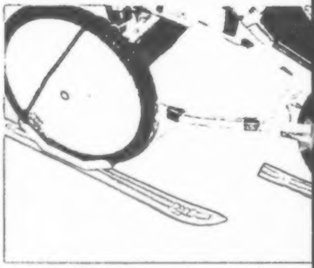
MPA

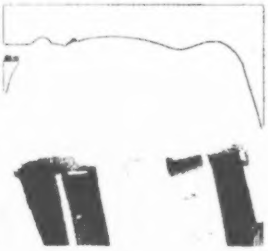
For subscription and advertising information, see page 74

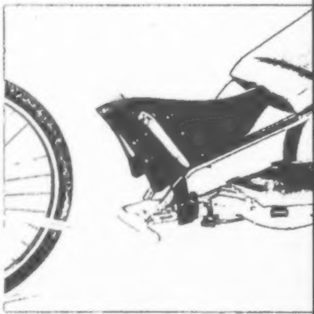
The KANGOO





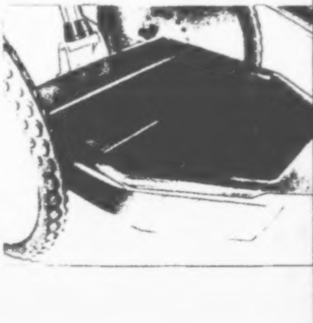






Imagine a product that lets you jog with your child through a park, take her for a bicycle ride through your neighborhood, or let him experience the joys of cross country skiing...You've just purchased a Kangoo, the only mobility base that provides these opportunities. The Kangoo allows your child to experience the outdoors like no other product.

The Kangoo easily folds to fit into the trunk of your car or store in the closet. Made from high-grade aluminum, it is light enough for anyone to handle, and durable enough to provide many years of use. A high quality shock absorber provides optimum comfort for your child even when traveling over the roughest of terrains, and the high quality wheels and axles require minimal effort to push the Kangoo.

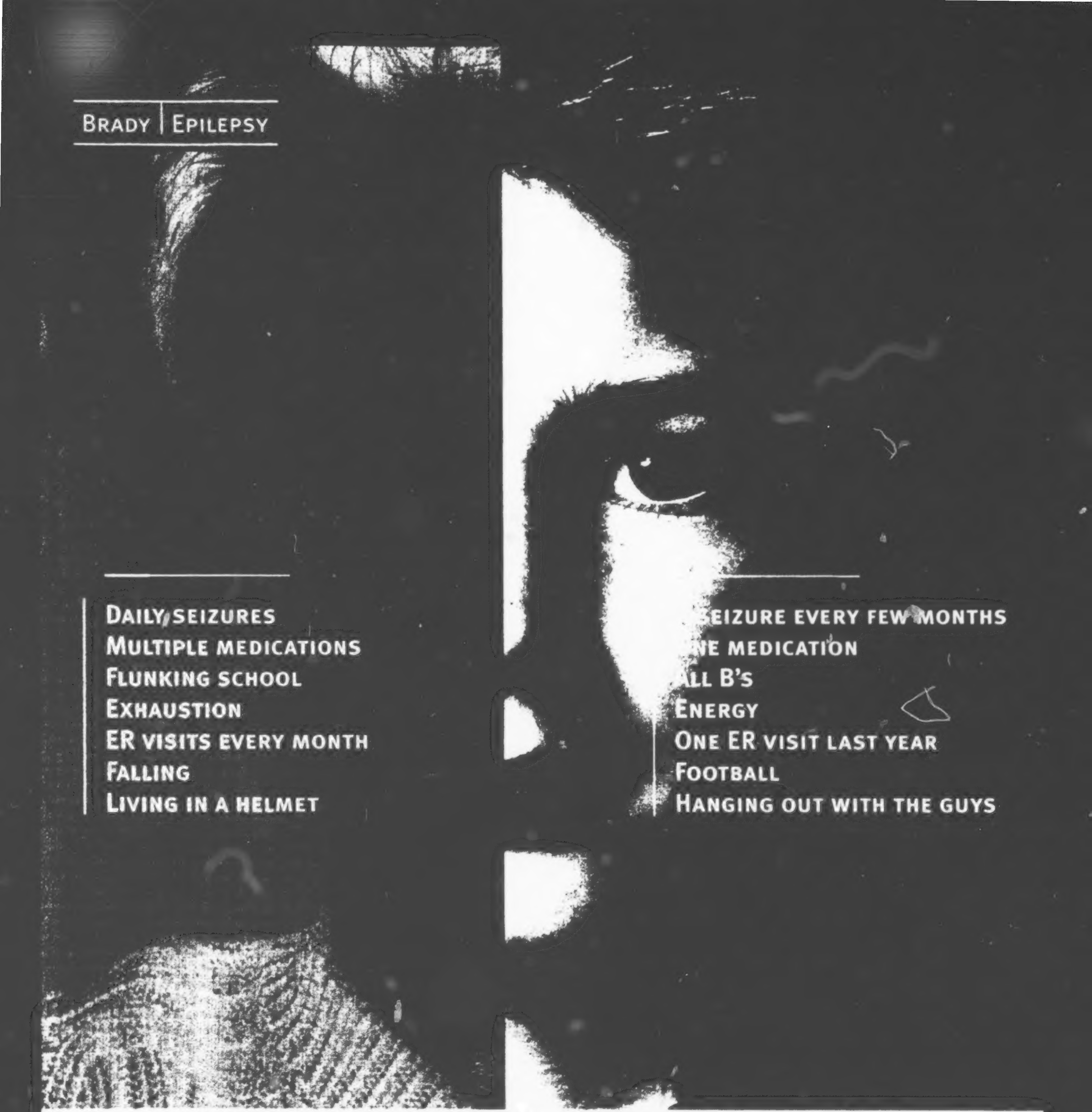


CALL SNUG SEAT NOW FOR YOUR FREE CATALOG

1-800-336-7684

Circle #45 or visit www.eparent.com/adinfo

SNUG SEAT®



BRADY | EPILEPSY

- DAILY SEIZURES
- MULTIPLE MEDICATIONS
- FLUNKING SCHOOL
- EXHAUSTION
- ER VISITS EVERY MONTH
- FALLING
- LIVING IN A HELMET

- SEIZURE EVERY FEW MONTHS
- ONE MEDICATION
- ALL B'S
- ENERGY
- ONE ER VISIT LAST YEAR
- FOOTBALL
- HANGING OUT WITH THE GUYS

AN EXTRAORDINARY PROMISE — AN ORDINARY LIFE

If you or someone you love has had their life turned upside down by epilepsy, an everyday, ordinary life can be the most extraordinary promise of all.

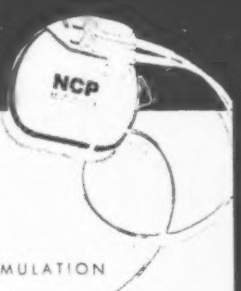
So if you're dissatisfied with the quality of life and seizure control you've had from anti-seizure medications, or you've found their side effects intolerable, discover the difference that VNS Therapy™ can make.

VNS Therapy has been used by over 15,000 patients like Brady with refractory epilepsy that hasn't responded to multiple medication regimens.

If at least two anti-seizure medications haven't worked, ask your doctor about adding VNS Therapy. It's not brain surgery. It's a medical device the doctor implants in the chest, with leads that run up to the vagus nerve in the neck.

It provides significant seizure control for many patients, with no debilitating side effects, and improvement in alertness, fatigue and mood. Some patients are even helped as dramatically as Brady, although VNS results may vary.

BEST COPY AVAILABLE



VNS Therapy is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures that are refractory to antiepileptic medications. See your Neurologist or Surgeon for all reported and potential side effects, warnings, precautions, and contraindications related to VNS.

Do something extraordinary today. Ask your doctor if VNS Therapy is right for you. Call us at **1-866-281-4686**. And visit our Web site at www.cyberonics.com. Your whole life is waiting.

VNS THERAPY

VAGUS NERVE STIMULATION

Cyberonics

Circle #25 or visit www.eparent.com/adinfo

EXECUTIVE SUMMARY[1]
SAFETY INFORMATION
FOR THE NCP® SYSTEM

INTENDED USE / INDICATIONS – UNITED STATES

The NCP System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures which are refractory to antiepileptic medications.

CONTRAINDICATIONS

- The NCP System cannot be used in patients after a bilateral or left cervical vagotomy.
- Do not use short-wave diathermy, microwave diathermy, or therapeutic ultrasound diathermy on patients implanted with the NCP System. Diagnostic ultrasound is not included in this contraindication.

WARNINGS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals. This is not intended to serve as a substitute for the complete NCP System Physician's Manual.

⚠ The **safety and efficacy** of the NCP System has not been established for uses not covered in the "Intended Use/ Indications" section of the manual.

⚠ The safety and efficacy of the NCP System treatment has not been established for stimulation of the **right vagus nerve** or of any other nerve, muscle, or tissue.

⚠ **Excessive stimulation** at a combination of high frequency (≥ 50 Hz) and an excess duty cycle (that is, one that occurs when ON time is greater than OFF time) has resulted in degenerative nerve damage in laboratory animals. An excess duty cycle can be produced by continuous or frequent magnet activation (> 8 hours), as determined by animal studies. Cyberonics recommends against stimulation at these combinations of ranges.

⚠ **Aspiration** may result from the increased swallowing difficulties reported by some patients during stimulation. Patients who have **pre-existing swallowing difficulties** are at greater risk for aspiration.

⚠ **Device malfunction** could cause painful stimulation or direct current stimulation. Either event could cause nerve damage and other associated problems. Patients should be instructed to use the magnet to stop stimulation if they suspect a malfunction, and then to contact their physician immediately for further evaluation. Prompt surgical intervention may be required if a malfunction occurs.

⚠ Susceptible patients with predisposed cardiac conduction systems (re-entry pathway) have not been studied as part of controlled clinical trials to establish the safety of NCP system treatment in these patients. Evaluation by a cardiologist is recommended if the family history, patient history, or electrocardiogram suggests an abnormal cardiac conduction pathway. Serum electrolytes, magnesium, and calcium should be documented before implantation. Post-implant electrocardiograms and Holter monitoring are recommended if clinically indicated.

⚠ **Sudden unexplained death in epilepsy (SUDEP):** Through August 1996, 10 sudden and unexplained deaths (definite, probable, and possible) were recorded among the 1,000 patients implanted and treated with the NCP device. During this period, these patients had accumulated 2,017 patient-years of exposure. Some of these deaths could represent seizure-related deaths in which the seizure was not observed, at night, for example. This number represents an incidence of 5.0 definite, probable, and possible SUDEP deaths per 1,000 patient-years. Although this rate exceeds that expected in a healthy (nonepileptic) population matched for age and sex, it is within the range of estimates for epilepsy patients not receiving vagus nerve stimulation, ranging from 1.3 SUDEP deaths for the general population of patients with epilepsy, to 3.5 (for definite and probable) for a recently studied antiepileptic drug (AED) clinical trial population similar to the NCP System clinical cohort, to 9.3 for patients with partial onset epilepsy.

⚠ **The NCP device is not curative:** Physicians should warn patients that the NCP System is not a cure for epilepsy and that since seizures may occur unexpectedly, patients should consult with a physician before engaging in un-supervised activities, such as driving, swimming, and bathing, and in strenuous sports that could harm them or others.

⚠ **Obstructive Sleep Apnea:** Patients with obstructive sleep apnea (OSA) may have increased apneic events during stimulation. Cyberonics recommends care when treating patients with preexisting OSA. Lowering stimulus frequency or prolonging OFF time may prevent exacerbation of OSA.

PRECAUTIONS

Physicians should inform patients about all potential risks and adverse events discussed in the NCP System physician's manuals.

⚠ **Laryngeal irritation** may result from stimulation. **Patients who smoke** may have an increased risk of laryngeal irritation.

⚠ **Dyspnea** may result from stimulation. **Patients with chronic obstructive pulmonary disease** may have an increased risk of dyspnea.

⚠ It is important to follow **recommended implantation procedures and intraoperative product testing** described in this manual. During the intraoperative Lead Test, rare incidents of bradycardia and/or asystole have occurred. As of October 1998, approximately 3,000 patients had been implanted with the NCP System. Four of these patients were reported to have experienced **bradycardia and/or asystole** during the intraoperative Lead Test. All four patients recovered without sequelae. One of the four patients was implanted with the NCP System. There were no postoperative or VNS-treatment-related cardiac adverse events later reported for that patient. No similar events were reported to have occurred during the clinical studies at the time of implantation or during treatment. The safety of this therapy has not been systematically established for patients experiencing bradycardia or asystole during NCP System implantation.

⚠ **Reversal of lead polarity has been associated with an increased chance of bradycardia** in animal studies. It is important to make sure that the Lead connector pins are correctly inserted (white marker to + connection) into the Pulse Generator header.

⚠ It is important to follow **infection control procedures**. Infections related to any implanted device are difficult to treat and may require that the device be explanted. Cyberonics recommends that the patient be given antibiotics preoperatively. The surgeon should ensure that all instruments, including the NCP Tunneling Tool, are sterile prior to the operation.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve** in the neck area inside the carotid sheath.

⚠ The NCP System is indicated for use only in stimulating the **left vagus nerve below where the superior and inferior cervical cardiac branches separate from the vagus nerve.**

⚠ A **neck brace** can be used by the patient for the first week to help ensure proper Bipolar Lead stabilization.

Environmental and Medical Therapy Hazards

⚠ Patients should exercise reasonable caution in avoiding devices that generate a **strong electric or magnetic field.** (For examples, see the "Other Environmental Hazards" section of the Physician's Manual.) If a Pulse Generator ceases operation while in the presence of electromagnetic interference (EMI), moving away from the source may allow it to return to its normal mode of operation.

⚠ NCP System operation **should always be checked** by performing device diagnostics after any of the procedures mentioned in the Physician's Manual.

⚠ Because of where the Pulse Generator is implanted in the chest, **patients may need to be specially positioned in mammography equipment for clear imaging.** Otherwise, the device may be seen as a shadow on the mammogram. (Most routine diagnostic procedures, such as fluoroscopy and x-radiography, are not expected to affect system operation.)

⚠ **Therapeutic radiation** may damage the Pulse Generator's circuitry, although no testing ha been done to date and no definite information on radiation effects is available. Sources of such radiation include therapeutic x-rays, cobalt machines, and linear accelerators. The radiation effect is cumulative, with the total dosage determining the extent of damage. The effects of exposure to such radiation can range from a temporary disturbance to permanent damage, and may not be detectable immediately.

⚠ **External defibrillation** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for external defibrillation.

⚠ **Electrocautery surgery** may damage the Pulse Generator. Please refer to the Physician's Manual for complete instructions for electrocautery surgery.

⚠ **Magnetic resonance imaging** (MRI) should not be performed with a magnetic resonance body coil in the transmit mode. The heat induced in the Bipolar Lead by an MRI body scan can cause injury.

Use caution when other MRI systems are used, since adverse events may occur because o different magnetic field distributions.

⚠ No scan in which the radiofrequency (RF) is transmitted by the body coil should be done on a patient who has the NCP System. Thus, protocols must not be used which utilize local coils that are RF-receive only, with RF-transmit performed by the body coil. Note that some RF head coils are receive only, and that most other local coils, such as knee and spinal coils, are also RF-receive only. **These coils must not be used in patients with the NCP System.**

⚠ **Therapeutic ultrasound.** Routine therapeutic ultrasound could damage the Pulse Generator and may be inadvertently concentrated by the device, causing harm to the patient.

⚠ **Extracorporeal shockwave lithotripsy** may damage the Pulse Generator. If therapeutic ultrasound therapy is required, avoid positioning the Pulse Generator part of the body in the water bath or in any other position that would expose it to ultrasound therapy. If that positioning cannot be avoided, program the Pulse Generator output to 0 mA for the treatment, and then after therapy, reprogram the Pulse Generator to the original parameters.

Diagnostic ultrasound is not expected to affect the NCP System.

⚠ The Pulse Generator may affect the operation of **other implanted devices,** such as cardia pacemakers and implantable defibrillators. Possible effects include sensing problems and inappropriate Pulse Generator responses. If the Pulse Generator patient requires concurrent implantable pacemaker and/or defibrillator therapy, careful programming of eac system is necessary to optimize the patient's benefit from each device.

ADVERSE EVENTS

Adverse events reported during clinical studies as statistically significant are listed in alphabetical order Ataxia (muscle movements or twitching, generally associated with stimulation); Dyspepsia (indigestion); Dyspnea (difficulty breathing, shortness of breath); Hypesthesia (impaired sense of touch); Increased coughing; Infection; Insomnia (inability to sleep); Laryngismus (throat, larnx spasms); Nausea; Pain; Paresthesia (prickling of the skin); Pharyngitis (inflammation of the pharyn throat); Voice alteration (hoarseness);Vomiting.

Other potential adverse events possibly associated with surgery or stimulation include but are no limited to the following:

Aspiration (fluid in the lungs); Blood clotting; Choking sensation; Damage to nerves or vasculature i the surgical area, including the carotid artery and jugular vein; Device (Generator and/or Lead) migration or extrusion; Dizziness; Dysphagia (difficulty swallowing); Duodenal ulcer, gastric ulcer; Ear pain; Facial flushing; Facial paralysis, paresis; Foreign body reaction to implants, including possible tumor formation; Formation of fibrous tissue, pockets of fluid; Heart rate and rhythm changes; Hiccuping; Incision site pain; Irritability; Laryngeal irritation (sore, painful throat); Left hemidiaphragm paralysis; Left recurrent laryngeal nerve injury; Left vocal cord paralysis; Low-grade fever; Muscle pain; Neck pain; Nerve injury; Painful or irregular stimulation; Skin, tissue reaction; Stomach discomfort; Tinnitus (ringing in the ears); Tooth pain; Unusual scarring at the incision site; Urinary retention; Vagus nerve paralysis; Weight change; Worsening of asthma and bronchitis; Worsening of cardiac abnormalities, including heart rate and rhythm.

⚠ Patients who manipulate the Pulse Generator and Bipolar Lead through the skin may damag or disconnect the Bipolar Lead from the Pulse Generator and/or possibly cause damage to th vagus nerve.

---

[1] The information contained in this Executive Summary for Physicians represents partial excerpts of important prescribing information taken from the *NCP Pulse Generator Physician's Manual*. The information is not intended to serve as a substitute for a complete and through understanding of the material presented in all of the Physician Manuals for the NCP System and its component parts nor does this information represent full disclosure of all pertinent information concerning the use of this product, potential safety complications, or efficacy outcomes.

editor's desk

A LEGLESS REPORT GIVES BIRTH TO A NEW ACADEMY

In February of 2002, Surgeon General David Satcher released his Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. In the foreword to his report, Dr. Satcher states, "It became apparent that, as our system of care for those with mental retardation evolved, our attention to their health needs lessened."

The Surgeon General's Report directs those of us who care for persons with developmental disabilities toward six strategic goals which will "close the gap" in the delivery of health care to this population of Americans. Page nine of Dr. Satcher's National Blueprint, Goal 4: Train Health Care Providers in the Care of Adults and Children with Mental Retardation, addresses the lack of professional training in the care of persons with developmental disabilities.

Dr. Satcher observes, "The challenges and rewards of treating individuals with MR are rarely addressed in the training of physicians and other health care professionals. However, anecdotal evidence and limited data indicate that opportunities for clinical ezperiences with these patients, early in medicla and other health professions training, increase the capacity of providers to value and accept these patients into their practices."

Candidly Dr. Satcher has often expressed his dismay (and the reality) that the Reports of the Surgeon General "don't have legs" and unless motivated and committed individuals translate the reports into action, the reports will frankly remain interesting artifacts.

But how do you translate the need to train the next generation of physicians and dentists to care for people with disabilities into innovative curriculums, clinical opportunities and rewarding careers? You congeal a group of like minded rogues on which someone says, "Who wants to be the president?" after realizing that everyone has dropped the ball (or never thought of picking it up).

Exceptional Parent magazine takes great pleasure in announcing the establishment of The American Academy of Developmental Medicine and Dentistry.

The academy's president is Dr. Phil May, Clinical Associate Professor of Medicine at the Robert Wood Johnson Medical School and Chief of Medicine at the Hunterdon Developmental Center (Clifton, New Jersey). Phil has been a pioneer in the creation of medical undergraduate and postgraduate programs in neurodevelopmental disorders.

By chance at the Surgeon General's Conference Phil met his dental counterpart Dr. Henry Hood. Henry is a Clinical Assistant Professor at the University of Louisville School of Dentistry and the head of the Dental Clinic at the Hazelwood Center in Louisville. Like Phil, Henry has long seen the need to introduce students to the joys of making a difference in the lives of individuals with special healthcare needs.

Henry, the Academy's new Executive Director met Phil again at the Chicago meeting of Special Care Dentistry. Phil was one of five "physicians" invited to participate in a presentation on "Physician - Dentist Collaboration" (they do after all work on the same body). This novel meeting (the brainchild of Special Care Dentistry President Dr. Paul Glassman) of physicians and dentists involved in specialized health care must have initiated some major brain flossing cause things have never been the same to these pioneers.

Catalyzed by developmental psychiatrist Dr. Steven Zelenski of the University of Wisconsin's Weisman Institute, (so let's see we got the body, mouth and mind covered so far) the proposal to incubate the American Academy of Developmental Medicine and Dentistry was formalized on May 15th, 2002.

Dr. May, in describing the Academy's (AADMD) National Action Strategy aimed at giving the Surgeon General's Report some legs offered, "We believe part of the solution to the problem can be found by promoting collaborations between physicians and dentists in the community, between medical schools and dental schools, and between Human Services programs, which currently exist in institutions, with those in the community."

Working in parallel with the new Academy was Dr. Steve Perlman (a member of the EP Dental Advisory Board) who's work with the Special Olympics "Healthy Athletes" initiative led to compelling Senate hearings which served as the footprints to the Surgeon General's Report. If Steve led the footprints then it surely was Dr. Sandy Fenton (Chair of the Community Dentistry Program at the University of Tennessee's School of Dentistry) who provided the hoofbeats with his successful championing of the cause of oral health for people with disabilities with the American Dental Association.

Pioneers, rogues, visionaries...the stuff of a new Academy, an Academy born out of a report that cried out for legs.

Membership is open to physicians, dentists, allied health professionals and persons interested in the promotion of improved healthcare to people with neurodevelopmental disabilities. EP

THE AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY
Henry Hood, DMD, Executive Director, Hazelwood Center,
1800 Bluegrass Avenue, Louisville, KY 40215
Tel (502) 368-2348 E-mail: henry.hood@mail.state.ky.us

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief
Director, Morton J. Kent Habilitation Center
Orange Grove Center, Chattanooga, TN

Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received about a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: EP Magazines, Attn.: Search/Respond, 65 East Route 4, River Edge, NJ 07661; Fax to: (201) 489-0074; e-mail to epedit@aol.com; or visit Search & Respond on our web site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2002 Resource Guide (January 2002, starting on page 22).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Adaptable Socks

My ten-year-old with Down Syndrome has especially poor, fine motor skills and is unable to dress himself. With the right socks, however, he might be able to pull on his own socks. They must be tube socks with no heel, and stretch easily so he can make them very wide, and should be ankle length. Perhaps stretchy terry material would work. I'd be interested in any leads on how to find such socks.

—LM via EP Web Site

S

School Bus Schedule Problems

I have a 16-year-old daughter who is diagnosed as having severe retardation, epilepsy, and mild cerebral palsy. She currently attends a special education classroom in another school district and is now being picked up from school a half hour after school lets out and she gets home from school an hour later. The school she attends is only 15 minutes away from home, but her wheelchair bus, after picking her up, is then picking up other kids from other schools. The district says she can be kept on the bus for up to 90 minutes. She is exhausted and lethargic when she gets home, but school officials tell me 90 minutes is a reasonable time and they will not consider changing the bus route. Has anyone had this problem and solved it?

—NM via EP Web Site

S

Problems with Toilet Training

Our seven-year-old grand daughter has athetoid cerebral palsy. She is a very bright child, understands everything and has just started using the Dynavox to communicate. She is in school and they are talking of mainstreaming her next year. My problem is toilet training. We have been working on it for about two years now. At first she would point if she needed to potty, then we got a little recorder to strap to her leg so she could tell us, but she now only does it so inconsistently. If we take her every hour or so she will usually do real well without any accidents, but if we leave it to her to inform us when she needs to go, she seldom tells us. I was wondering if anyone out there had a similar situation or had any suggestions on toilet training.

—F via EP Web Site

S

Lip Biting

We have a three-year-old daughter with CP who has a habit of biting her lower lip. She was recently sent home from school because she bit herself pretty bad and her teachers and therapist said that they have never seen that before. Has anyone out there overcome a similar situation?

—RP via EP Web Site

S

Double Strollers

Hi, I am the mother of two girls with an unknown genetic disorder. They are two and thirteen. Both have multiple disabilities such as seizures, cataracts, gastroesophogeal reflux, and low muscle tone. Neither one can sit unsupported, walk or talk, and both need a lot of special attention. I am currently looking for any information on a double stroller for the two of them. I need to be able to get them to the doctor and therapy sessions and I do not always have someone available to help. The stroller needs at be able to accommodate a toddler and a young teen. If anyone knows of one out there that would work, please let me know.

—RC via EP Web Site

S

Walking Restraints

I am working with a five-year-old boy in the school district who has autism and mild cere-

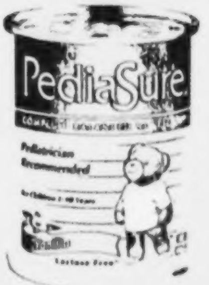
continued on page 19

Clay, Danny, Robin and Danielle Wagner live in Fort Lauderdale, Florida. Clay is autistic and has a seizure disorder.

"We're a PediaSure® Family."

"PediaSure helps us give Clay the nutrition he needs."

All kids need proper nutrition for growth and development. If your child is not getting enough of the right nutrition from regular food or has special feeding needs, ask your doctor about the complete, balanced nutrition of PediaSure. It's specially formulated to provide children with proper amounts of protein, fat, carbohydrate, vitamins and minerals. Available in your local supermarket, drug or discount store.



Available through WIC®*

*If your child has special dietary needs, check with your physician or local WIC clinic to see if your child is eligible to receive PediaSure through the WIC program. WIC is a registered trademark of the U.S. Dept. of Agriculture.

© 2001 Abbott Laboratories

Circle #43 or visit www.eparent.com/adinfo

HARD MANUFACTURING

AGE APPROPRIATE
BEDS

For when your child passes the crib stage!

Dianna Fitzgerald
& Her Son Nicholas

The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

It truly is the best investment we ever made.

Thank You HARD!
Dianna Fitzgerald

- HARD "Age Appropriate" Beds accommodate your child with the safety and convenience you would expect from the nation's #1 manufacturer of hospital cribs and youth beds.
- Available in a rainbow of colorful epoxy finishes and laminate colors to match your room decor.
- Hi-Lo adjustment for convenience and safety.
- Attains all orthopedic and comfort positions.
- Currently available in custom sizes to accommodate all ages.
- Crib type safety sides are close to the mattress to protect arms & legs.

For information about our full line of beds and cribs,
as well as locating your nearest HARD dealer, please give me a call.
Kevin, *Home Health Consultant*

1-800-873-4273 ext. 267

HARD
MANUFACTURING CO. INC.
Buffalo, New York • 1-800-USE-HARD

Choose HARD... So life can be a little easier!

Circle #33 or visit www.eparent.com/adinfo

Limited Time Offer

Give the Gift of Knowledge That Continues to Give ALL YEAR LONG

A Subscription to EP Magazine

EP is the best support network for an Exceptional Parent Now you can make this available at a substantial DISCOUNT: JUST $24!

If you already subscribe to EP, a gift subscription is ONLY $19.95!

That's:

- **12 issues including the *2003 Annual Resource Guide,***
- **AND as our special gift to you, a copy of the inspirational book, *Patient Persistence* (a $19.95 value).**

Called "...an extraordinary tribute to the *'Indelible Human Spirit'*", this 190+ page book contains practical wisdom as well as moving accounts of individual courage.

Circle #199

GIVE THE GIFT OF KNOWLEDGE

I am already a subscriber and I want to give a subscription to someone else

☐ 1 year $19.95 ☐ 2 year $43.95 ☐ 3 year $67.95

US Funds vary. Canadian add $10 per year. Other foreign countries add $15 per year.

To get this special offer you must send this card or call toll-free 877-372-7368 and mention **Limited Offer XSDEC2**

PLEASE SEND MY GIFT OF EP TO:

Name __________

Address __________

City __________

State __________

Zip _____ County _____

THIS GIFT IS FROM:

Name __________

Address __________

City __________

State _____ Zip _____ County _____

☐ Check enclosed. (use separate envelope)

☐ Bill me later. ☐ AMEX ☐ VISA

☐ MASTERCARD (use separate envelope)

Account Number __________

Exp. Date __________

Signature __________

(Offer good on new subscriptions only. Expires 2/1/03)

XSDEC2

GIVE THE GIFT OF KNOWLEDGE

I am not a subscriber but I want to give a subscription to someone else

☐ 1 year $24 ☐ 2 year $48 ☐ 3 year $72

US Funds vary. Canadian add $10 per year. Other foreign countries add $15 per year.

To get this special offer you must send this card or call toll-free 877-372-7368 and mention **Limited Offer XSDEC2**

PLEASE SEND MY GIFT OF EP TO:

Name __________

Address __________

City __________

State __________

Zip _____ County _____

THIS GIFT IS FROM:

Name __________

Address __________

City __________

State _____ Zip _____ County _____

☐ Check enclosed. (use separate envelope)

☐ Bill me later. ☐ AMEX ☐ VISA

☐ MASTERCARD (use separate envelope)

Account Number __________

Exp. Date __________

Signature __________

(Offer good on new subscriptions only. Expires 2/1/03)

XDEC2

GET THE GIFT OF KNOWLEDGE

EP
Exceptional Parent

YES! I WANT TO BE PART OF THE EXCEPTIONAL PARENT NETWORK...AND GET THE 2003 RESOURCE GUIDE AT NO EXTRA COST

☐ 1 Year (12 issues) $24 ☐ 2 Years (24 issues) $48 ☐ 3 Years (36 issues) $72

US funds vary. Canada add $10 per year. Other foreign countries add $15 per year.

To get this special offer you must send this card or call toll-free 877-372-7368 and mention Limited Offer BDEC2

☐ Check enclosed. (use separate envelope) ☐ Bill me later.

☐ AMEX ☐ VISA ☐ MASTERCARD (use separate envelope)

Account Number __________ Exp. Date _____

Name __________

Address __________

City _____ State _____ Zip _____ County _____

E-mail __________ Yes, I want more information to help me everyday.

Signature __________

(Offer good on new subscriptions only. Expires 2/1/03)

BDEC2

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO 534 MARION OH

POSTAGE WILL BE PAID BY ADDRESSEE

EXCEPTIONAL PARENT
PO BOX 2078
MARION OH 43306 2178

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others who are providing a richer life for themselves and for their children.

Exceptional Parent's MISSION

IS TO BE THE PREMIER
INFORMATION
SOURCE FOR PARENTS
EDUCATORS AND
HEALTHCARE
PROFESSIONALS
DEDICATED TO CARING
FOR CHILDREN AND
YOUNG ADULTS
WITH SPECIAL NEEDS

Don't miss a single issue:

SUBSCRIBE TODAY AND
RECEIVE THE 2003
RESOURCE GUIDE
GO ONLINE AND
SAVE EVEN MORE

EP
Exceptional
Parent

www.eparent.com

continued from page 14

bral palsy. He is an independent walker physically, but does not understand any safety issues, so his parents have to hold his hand all the time or use a stroller. When his mom holds his hand he is always trying to pull away or go in a different direction than she is. This is very hard on her back and she would like to know if anyone has ideas for a harness-type tether system that would keep him safely connected to her but she wouldn't have to hold his hand. We are also concerned that the system does not cause him to trip or get pulled off balance.

—SL via EP Web Site

Reading Problems with CP

My son is 11 years old and has a diagnosis of cerebral palsy and more recently, autistic spectrum disorder with regard to sensory processing. My son has great memory capability but cannot focus in order to read or write. Not one program in either the various school or non-school settings have been successful to help him learn to read. He can only recognize site words occasionally — it seems to be intermittent, not on a regular basis. We have had him tested just about everywhere and all come up with same diagnosis but no suggestions to help him learn to read. I would appreciate hearing from other families regarding what programs they have found to be successful with any children with similar-diagnoses. Can anyone help us? Thank you.

—LP via EP Web Site

Respond

Lattice Corneal Dystrophy

DE has a five-year-old grandson with Lattice Corneal Dystrophy, and is looking for further information or support regarding this condition.

We have a nearly six-year-old grandson with the same diagnosis. As I'm writing this note, we are in a dark room so he can play. He's enrolled in Kindergarten, but has been out three out of five days this week. So far we've been given no hope and can only deal with the situation as best as we can. He was misdiagnosed and mistreated for three years.

I was glad to see your request for help; we'd also like to know of anything that could be done. The doctor says to expect a corneal transplant down the road, but we'd like to hear of some relief right now.

— SP Kentucky

Rett Syndrome

Anonymous is looking to know where to find information on Rett Syndrome.

My daughter was diagnosed by her neurologist with Rett Syndrome in March of 2001. Often times, Rett Syndrome is misdiagnosed as Cerebral Palsy, as was the case with my daughter. This is due to similarities between the conditions and the fact that Rett Syndrome is rare and often unknown, even to medical professionals. The International Rett Syndrome Association is a great resource that would supply the information you're looking for as well as referral service, parent support contacts, and support research. Call 1-800-818-RETT, email them at irsa@rettsyndrome.org or visit their web site at www.rettsyndrome.org

—AW via e mail

DR. FEUDTNER'S NOTE: In addition to the resources mentioned above and in the orginal Search, one can also turn for additional information to the Rett Syndrome Research Foundation (www.rsrf.org).

Assistive Technology Help

DM is searching for information on what kind of computer to get for her home, especially one that is able to use the Internet and is compatible with having a cause-and-effect device installed for programs.

I believe that every state has technology assistance centers. Here in Florida, where we are known for having few resources, we have two excellent centers for technology, FAAST and ATEN. You should be able to find out how to contact the center in your state by looking in EP's annual resource guide. These types of centers were all listed together in one area. I recommend working with a non-profit center rather than going to a commercial web site because the former has no financial interest in your purchasing any specific product. I also advise you to work with a center where you can visit and see things first hand.

—CH via e-mail

Swim Diapers

CD has a 12-year-old son and is looking for some adult-sized swim diapers for him to wear in the pool.

At the World Congress on Disabilities there were at least four vendors selling reusable swim diapers. Two that I know of are Gabby's and Adrian's Closet. Erich Schnur from HA Bruno (eschnur@wcdexpo.com) should be able to give you contact information. Sportime/Abilitations also sells swim diapers (www.abilitations.com)

—CH via e-mail

I had the same problem finding a swim diaper for my daughter who is 16 years old. I finally found one from My Pool Pal-

continued on page 20

continued from page 19

Aqua Force (www.aquaforce.com). We have used them and they worked great for us. I have also found a couple of other companies with youth and adult swim diapers, including ATD (www.atdincdirect.com) and swimdiapers.com. You can check them out and see what is best for your son.

— SA, via e-mail

Reading Programs

B is looking to find ideas for a reading program for a 10-year-old girl with autism.

I have had much success over the years with the Edmark reading system. It is very systematic and concrete, both important characteristics for students with autism. It also does not require speech or phonetics. Our current emphasis on phonetic awareness and phonemic production is not very helpful to students who are nonspeaking or have other language difficulties. My other suggestions are that people with autism or related disorders, as well as persons with hearing impairments, tend to be very literal in their thinking. They may have difficulty manipulating fictional scenarios in their minds. Typical reading series for young readers tend to be fiction-based and this material may be very hard for some students to comprehend.

You may have more success focusing on reading for functional purposes such as learning about vacation destinations, reading recipes and directions, and looking through catalogs. Another option is creating your own reading materials based on factual information about something your student is particularly interested in. I have found that many people with autism are tremendously interested in facts about one or more subjects.

Some students may never enjoy reading fiction. Others may learn to enjoy it after they have had plenty of time to become fluent readers using text that makes sense to them.

— CH via e-mail

Comunication Problems

PA is looking for ways to communicate with her five-year-old son, who visually impaired and has hearing loss and is developmentally delayed.

Each state in this country has a program that serves children who are deaf-blind. This term does not mean that the child is completely deaf or blind, rather that the child suffers from a loss of both. You can check up the different states on the web at www.tr.wou.edu/dblink.

I work for the Deaf-Blind Program in South Dakota. The neat thing about these programs is that we accept the child as a whole. Lots of children have additional disabilities, and we work with all of them to make their lives easier.

—TN via e-mail

I work with children who have visual and hearing impairments. In our program, we use a system called tangible symbols. It uses three-dimensional cues to represent activities, objects, or places, such as "outside," which may be represented by some pebbles mounted on cardboard. You can start using these symbols by handing them to him when you begin an activity with that place or object represented. Eventually, he can begin handing you the symbols to express his desires. It's hard to carry around all these symbols, so you should try to make the cues as small as possible but still meaningful to your son.

Also, if your son's vision is good enough, he may be able to use simple line drawings (enlarged, if necessary) to symbolize words and ideas, instead of three-dimensional objects. There are a lot of good picture symbol stems out there. You can ask your son's speech/language pathologist about them.

— HV, Brooklyn, NY

Looking for Diagnosis

D&CP are looking for a diagnosis for their 16-month-old daughter, who has gross motor skills, very loose joints, and low muscle tone.

I have a son that is almost five years old who has a rare genetic disorder called Angelman Syndrome. Very few doctors or even neurologists have heard of it. Many parents with children who have Angelman Syndrome are misdiagnosed as having cerbral palsy or autism. We were fortunate that our son was diagnosed as having Angelman Syndrome at 15 months old, as the neurologist had seen Angelman in the past. For more information, go to the website www.angelman.org.

— D&R via EP Web Site

Seeking A Respondant!

A response to our homeschooling story in September's Parent Perspective from levernia@aol has Dynavox Corp. very interested in helping. Unfortunately, the email address is not operating and we would like to hear from her. Please write to dmazzella@eparent.com so that we can put you in touch with the company.

Epilepsy Research Project Needs Volunteer Families

If you or a member of your family has epileptic episodes, EP Magazine is asking you to participate in a new research project. Slated to begin in 2003, it will primarily center on non-medical aspects but with some questions on comorbity and other conditions. This highly confidential survey will attempt to quantify eplieptic incidence and other data. Please email epedit@aol.com or write to

Survey
EP Magazine
65 East Route 4
River Edge, NJ 07661

Who will care for your disabled child when you are gone?

Litigators Incorporated, P.C. & Affiliated Law Firms

ATTORNEYS ACROSS THE NATION

Dear Parents:

My sister died leaving behind a disabled child. If you have a child with a disability, the obligation for his or her care continues even after you are gone. My name is Jeff Brody, President of Litigators Incorporated, P.C. Let us help you find out if your child's disability was preventable; you could be entitled to substantial compensation for the lifetime care of your child. You owe it to your child to protect their future. There are time limits, please call me

Check out my web-site at www.thelitigatorsinc.com

Litigators Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States

Call Litigators Incorporated, P.C. NOW!

1-800-LAW-3350

Circle #37 or visit www.eparent.com/adinfo

INTERVIEW WITH DR. FRANCIS COLLINS

Dear Dr. Rader,

What an "exceptional" interview piece with Francis Collins by Lucinda O'Neill, highlighted in the October 2002 issue of Exceptional Parent. The future is indeed bright in anticipation of diagnosis and therapies for rare and more common diseases, education of health professionals from medical school to those in practice and for the advance preparation of ethical issues. Thank you.

Sincerely,
John Sarwark MD
Professor, Orthopedic Surgery
Northwestern University Medical School
The Children's Memorial Hospital

WCD

Dear Joe and Rick,

It was a pleasure and an honor to participate in what appeared to be a highly successful meeting. I think the mix of lay and professional attendees and speakers is the most appropriate format for mutual educational and collaborative efforts and I can only hope yours will serve as an example to other organizations, particularly in the rare disease community, as to how such interchange should be accomplished.

Kind regards,
Peter W. Stacpoole, Ph.D., M.D.
Professor of Medicine, Biochemistry and Molecular Biology
Director of Clinical Research,
University of Florida

AUTISM

Dr. Rader,

I was very disappointed you did not include the Autism Diagostic Observation Schedule (ADOS) and the Autism Diagnostic Interview (ADI) in your instruments used to assess autism. These two instruments, plus occupational, neurological, cognitive, and speech and language evaluations form the crux of state-of-the-art diagnosis of autism. Not only can we now diagnose autism around age 2, but science and research are pushing down the age of valid diagnoses. Early diagnosis is crucial to help these children, so please inform your readers not to wait if they suspect their young child is not developing typically. If your toddler does not regularly respond to his/her name when called and is not pointing, please have him screened for autism at a center that specializes in its diagnosis.

Sincerely,
Ketty Patiño González, Ph.D.
Clinical Assistant Professor of Psychology
University of Miami, Director, Autism Spectrum Assessment Clinic
Coral Gables, Florida

Dear Dr. Rader,

I realize that Exceptional Parent Magazine is meant primarily for parents rather than professionals, but lately there seems to have been a skew towards promoting, as opposed to presenting, alternative and unproven therapies. You previously heard from other physicians complaining about the apparent pro-bias for hyperbaric oxygen therapy in an article, despite the disclaimer that appears with every advertisement you accept. You have done a similar disservice, in my view, with the recent article summarizing alternative treatments for autism and other developmental disorders.

The author does note that, regarding sensory integration therapy, 'results in this area are preliminary at best', implying that every other approach has good research to support it. I have read Dr. Mehl-Madrona's text, and the fact is that there is no good evidence for the value of the therapies he describes, nor for their safety. Potential side effects such as cost, and time consumed, are not considered.

What is known about autism is that many children show marked spontaneous improvement between the ages of 3 and 6, regardless of therapy, pariticularly if they have some language skills going into that period. As such, any therapy conducted during this period is likely to seem successful for some children.

Conventional medicine certainly does not have good answers for the treatment of autism at present, and it is reasonable for Exceptional Parent to explore other options. However, I believe the magazine does owe parents your expert overview on controversial topics, rather than presenting them without comment, and, by implication, with your agreement.

Sincerely,
Jon Matthew Farber, M.D.

Dear Dr. Farber,

Thank you for the above email regarding Exceptional Parent Magazine's treatment of alternative therapies. It is our intent not to endorse alternative therapies, but to provide a forum for their discussion and further evaluation. This is in response to thousands of parents requesting information regarding these therapies. We do not endorse them, and indeed, clearly indicate that they are for the purpose of evoking discussions with physicians and other critical healthcare providers.

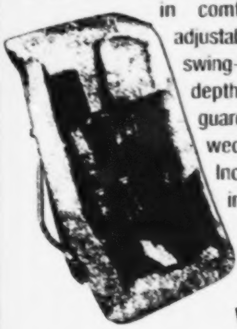
Rick Rader, MD
Editor in Chief,
EP Magazine

We encourage letters on any subject. Send them to: EP Magazine, Attn: Letter to the Editor, 65 East Route 4, River Edge, NJ 07661; Fax: (201) 489-0074; or E-mail: epedit@aol.com. Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified by full name and state. Please include your phone number and/or e-mail address on all correspondence.

Solutions for Daily Living
from Columbia Medical

Transporting

Since 1986, the **Columbia Orthopedic Positioning Seat** has been parents and therapists first choice in car seats. Suitable for children 20 to 102 lbs., it meets or exceeds all safety standards while offering the maximum in comfort, support and adjustability. Available with swing-away abductor, seat depth extender, buckle-guard and extensor thrust wedge accessories. Includes full-positioning pad set to customize fit and grow with the child.



Weighs only 11 lbs.

MOBILITY BASE

The Columbia Orthopedic Positioning Seat locks easily and securely onto the customized **Mobility Base.** The strong, lightweight frame offers three-angles of tilt and a height-adjustable footrest. Large wheels permit a smooth ride over any surface.

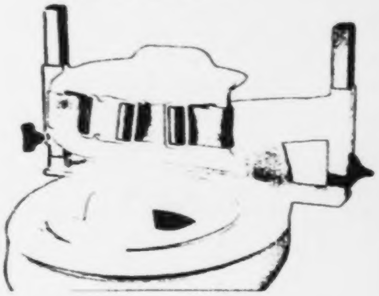
Bathing

Extension legs and casters are available to easily convert bath chair into a rolling shower chair.

Our NEW Fully Customizable Bath Chair, **Contour Ultima™** is completely configurable to meet an individual's unique needs. It offers the ultimate in positioning options and comfort. Available in four standard sizes and 192 custom-made combinations, the chair's seat, back leg length and seat width can be specified. The seat and back sections independently articulate providing full head and trunk support in both the sitting and reclining positions. Made of surgical grade stainless steel and replaceable ComfortMesh™ fabric. Includes two positioning belts for additional safety and security. The chair is sturdy, lightweight, easy to clean and fits in any standard tub.

Toileting

Our **Toilet Supports** attach and remove easily from any toilet. Available in both low and high backs, the supports can be used by children and adults.



Free Standing Bedside Positioning Commodes can be used independently or positioned over any standard toilet.

Columbia 800-454-6612 ext. 100

e-mail info@columbiamedical.com • www.columbiamedical.com

Since 1978, Columbia has manufactured products exclusively for individuals with special needs. All of our products are made in the USA of durable materials, are tested to the highest standards and are designed for maximum safety and comfort.

Circle #22 or visit www.eparent.com/adinfo

THE DIRECT SUPPORT PROFESSIONAL RECOGNITION ACT

Congressman Pete Sessions (R-Texas) and Congresswoman Lois Capps (D-California,) together with members of the American Network of Community Options (ANCOR,) have announced a resolution called the "Direct Support Professional Recognition Act." This legislation promotes greater attention on recruiting and retaining direct support professionals. The resolution highlights the shortage of trained direct support workers and will affect more than eight million Americans with developmental disabilities.

New Partnership Between Education Department and US Chamber of Commerce

In recognition of National Disability Employment Awareness Month, the US Department of Education has partnered with the US Chamber of Commerce's Center for Workforce Preparation, with the hope of helping employers reach out to the disability community to find qualified workers. In turn, the Education Department would offer its resources to the business community. The partnership was announced over the internet, as part of a Webcast entitled "Disability Employment 101: Learn to Tap Your Hire Potential." The event also featured officials from both government and private organizations discussing research, strategies and initiatives regarding disability employment.

Poison Emergency Kit

From HUMCO, a formulator of pharmaceutical products, comes a poison emergency kit, which brings poison awareness and safety to the home. Created in an effort between both HUMCO and the American Association of Poison Control Centers, the kit can be used to prepare parents to deal with dangerous situations with various toxins. The kit includes one ounce of ipecac syrup, one ounce of activated charcoal, a dosage cup, a Poison Emergency Information Guide, and a refrigerator magnet with the Poison Control Center's toll free number (800-222-1222). As mentioned in the product's literature, consumers are advised to contact the Poison Control Center before administering any of the syrup or charcoal from the kit.

New Bills Passed by Congress

On October 17, 2002, the Senate passed, both H.R. 4013, the Rare Diseases Act and H.R. 4014, the Rare Diseases Orphan Product Development Act, and will now go to President Bush for his signature. The Bills, which are sponsored in Congress by both Republicans and Democrats, are expected to increase rare disease research.

Homeownership for People with Disabilities

Fannie Mae is sponsoring a new mortgage loan called HomeChoice, designed to meet the needs of people with disabilities or those who have family members with disabilities living with them. This is reflected in their *American Dream Commitment*, a ten-year $2 trillion pledge to increase homeownership rates and serve 18 million targeted American families by the year 2010. It is currently available in 33 states with hopes to expand. To learn more about the HomeChoice program visit *http://www.efanniemae.com* or call 1-800-7FANNIE (1-800-732-6643).

The Gift of Giving

Time Inc. has introduced a new "Paddy Pillow" to their line called The Gift of Giving. Their products are designed to help adults and children communicate their feelings, so children can learn how to identify, understand and express emotions in a healthy way. Pillows come in both large and baby sizes and each contains a book. The Gift of Giving book features a "Paddy Pillow" expressing emotions associated with the holidays such as excitement, thankfulness, jealousy and disappointment. For more information visit http://www.paddypillow.com

Bill for Inclusive Schools Week

New Jersey legislators have proposed a bill to designate December 2-6 to be New Jersey Inclusive Schools Week, in recognition of the work done by parents, students, and school officials in maintaining a safe and inclusive educational environment.

NATIONAL ORGANIZATION ON DISABILITY WINS TWO MEDIA ACCESS AWARDS

The National Organization on Disability (N.O.D.) was the winner in two categories of the Media Access Awards presented by the California Governor's Committee for Employment of Disabled Persons last month. The honors went to the N.O.D. for both its redesigned web site (http://www.nod.org) as well as its public service announcement entitled "It's About Ability." N.O.D.'s newly designed web site was noted particularly for the accessibility of information that it offered. And the PSA, which featured a number of celebrity endorsements from figures like Harrison Ford, Christopher Reeve, Angela Basset, and Stevie Wonder, was also underwritten by sponsors Microsoft, the Presidential Task Force on the Employment of Adults with Disabilities, the McGraw-Hill Companies, and American Express.

Child Neurologists Honor International Rett Syndrome Association

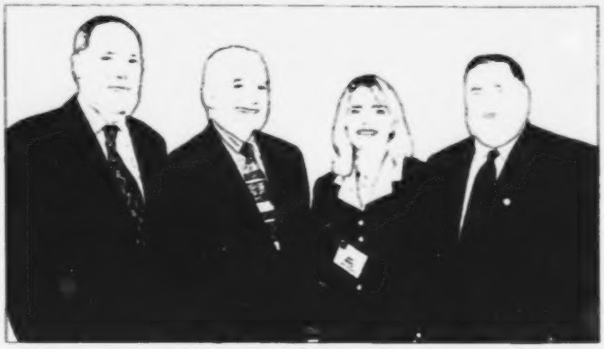
The First annual Patient Advocate Award of Merit has been awarded to the International Rett Syndrome Association (IRSA) by the Child Neurology Foundation. Kathy Hunter IRSA's President received the honor for outstanding public leadership among patient groups representing children with neurologic illnesses.

Kathy Hunter, President, IRSA

During the past several years the efforts of IRSA have led to significant advances in Rett Syndrome, a progressive developmental brain disorder affecting 1:15,000 newborn girls. The 18-year-old volunteer agency founded by the parents of children with this rare, life-altering disorder received widespread media attention during their advocacy efforts seeking increased funding from Congress. Among those providing compelling testimony was actress Julia Roberts, who earlier this year hosted and narrated the acclaimed documentary: Silent Angels, a nationally broadcast Discovery Health film about Rett Syndrome.

Since the group's founding by a small, but dedicated corps of parents in 1984, more than $35 million has been appropriated by Congress to the National Institutes of Health for the in-depth study of the disease, including $2.33 million in promising seed grants. Recently, the gene that determines this unusual disorder was identified.

"We are pleased to introduce this new award and to recognize this outstanding group of dedicated individuals for their efforts to link families affected by this tragic disease. The parents, physicians, and caregivers of the IRSA provide families the comfort and encouragement they deserve while ensuring that scientifically-sound information about this disorder is widely disseminated in a timely manner," said Dr. Kenneth Swaiman of the University of Minnesota, President of the Child Neurology Foundation at the annual meeting of the Child Neurology Society in Washington, DC.



From left to right: Steve Ashwal, MD, President, CNS; Ken Swaiman, MD, Chairman, CNF; Juile Vemmers Yannes, Chair of the Foundation Advocacy Committee; Joseph M. Valenzano Jr., Chairman of the Advisory Board to the Child Neurology Foundation.

Child Neurology Society President, Dr. Stephen Ashwal of Loma Linda University, CA praised the group for their internationally recognized patient database. "By establishing the MECP2 Variation (Rett Base) and Phenotype Databases, they have made it faster and easier for researchers to compare patients' mutations with their clinical symptoms while providing exciting opportunities for the discovery of new treatments!" Said Ashwal.

The 30-year-old Child Neurology Society is the professional organization representing more than 1,300 pediatric sub-specialists worldwide whose academic, research and practice careers are directed toward providing care to children with disorders affecting the brain and central nervous system. In 1999, the Child Neurology Society established the Child Neurology Foundation, a non-profit organization whose mission includes the development and funding of public and patient education, scientific research and advocacy initiatives on behalf of children afflicted with neurologic and developmental disorders.

Among the projects that will be undertaken are the collection, selection, and editing of materials to be formed into useful, pragmatic informational packets distributed to child neurologists worldwide. The material will also be distributed through the Foundation web site, ww.ChildNeurologyFoundation.org. and the EP ("Exceptional Parent") web site www.eparent.com that is linked to over 130 national organizations and associations.

ECHO Radio Program

The Ronald McDonald Children's Hospital of Loyola University Medical Center is now running a radio program called Every Child Has Opportunity (ECHO) in partnership with Lyons Township High School and WLTL-FM. There, young patients are given an opportunity to act as the DJs and talent of the radio station from 4 to 8 p.m. on the children's hospital floor. ECHO is made available by the hospital as part of its Reading, Writing, and Recovery School Program. The radio show features a number of subjects, including contests, giveaways, music, as well as children's news and health segments.

continued on page 26

continued from page 25

New Leadership at VSA

Very Special Arts (VSA arts) recently announced the appointment of new leadership to its organization. Soula Antoniou was named as the new president, while Mike Magee, MD was brought forth as board chair. Ms. Antoniou has been with VSA arts since 1993, and was recently selected as the executive director for the 2004 International VSA arts Festival. She was also successful in developing the VSA arts affiliate network, which now consists of affiliates in 49 states and the District of Columbia, as well as over 60 countries around the world. Mike Magee, MD, who was elected to the board of directors of VSA arts in 2001, is also the director of the Pfizer Medical Humanities Initiative, which allows him to speak internationally on a variety of health and public policy issues. In addition, he is a national spokesperson for the Senior Olympics, and has authored a number of books on medicine and other subjects.

The MDA and Mattie

Young poet Mattie J.T. Stepanek has accepted an invitation to serve a second year as the National Goodwill Ambassador for the Muscular Dystrophy Association. Mattie has a rare disease related to muscular dystrophy called mitochondrial myopathy. However, that hasn't stopped him from becoming the best-selling author of four books of poetry (Heartsongs, Journey Through Heartsongs, Hope through Heartsongs and Celebrate through Heartsongs). MDA National Chairman Jerry Lewis says of Mattie, "He expresses our message beautifully, and I know he'll move the hearts of millions more Americans next year as he's moved millions this year."

New Education Center for Children with Autism

The Department of Education unveiled a network of resources for improving education for autistic children when it announced a $5 million grant to set up the program. The network will be headquartered at the University of Washington and will include additional centers at five other institutions around the country: the University of Colorado at Denver; the University of South Florida; Ohio State University; the University of Kansas; and the Maryland Coalition for Inclusive Education. School districts throughout the US will be able to participate, as each will receive an expert from one of the six institutions involved to assess the district's specific needs. Afterwards, at one of the participating institutions, autism experts will host up to six educators from one school district at a time for a weeklong training session. A follow-up visit will be made to each school a month after each session to check up on the implementation of plans made during the training.

F.A.C.E.S. Art Day

Fight Against Childhood Epilepsy and Seizures (F.A.C.E.S.) hosted their sixth annual free art day on October 20, 2002 at The Children's Museum of the Arts in New York City, NY. It was a great opportunity for children with epilepsy to meet others, as well as parents to network with other parents. There were booths throughout the building for the kids to work on different art projects. There was also a face-painter and a balloon artist present. For more information and for news of next years event contact Christine Toes at (212) 779-2041.

AAMR F.Y.I

The AAMR FYI web site is now online. To access the site, visit http://www.aamr.org/FYI/ where visitors can find current and past issues of AAMR F.Y.I.

SCOTLAND DISABILITY AWARENESS SURVEY 2002 REPORT

Recently, Scotland's Disability Rights Commission conducted a survey of 1000 adults in Scotland to get an estimate of the public awareness of discrimination faced by the disabled community. The results of the survey found that 85% of those polled were aware of discrimination against people due to their disability, and even a greater majority (93%) felt that children should be taught about disabilities in school under the field of citizenship studies. More than half of those polled felt that people with disabilities are not given fair treatment in society, and almost two thirds think that the disabled are not properly represented in the government.

Outdoor Adventure Trips

Wilderness Inquiry is a non-profit organization which designs outdoor adventure trips for all people – including those with disabilities. The trips planned for February and March 2003 are canoe trips to tropical Florida Everglades and Boundary water ski and dogsled in Minnesota. These trips connect people of all ages, backgrounds and abilities so that everyone can learn to appreciate those that are different. For more information on these trips visit http://www.wildernessinquiry.org or call 612-676-9400.

NEVER PAY FULL PRICE AGAIN!!
EP PREFERRED BUYER CLUB OFFER!

A Charter Membership in the EP Preferred Buyer Club includes the following special benefits:

- *** A personalized EP Membership Card**
- *** 10% Discount on all books in the EP Library**
- *** 10% Discount on all videos in the EP Library**
- *** 20% Discount on all EP Monographs and Special Reports**
- *** $7.50 Discount on annual subscription to EP Magazine or renewal during term**
- *** One free ticket to the World Congress Exposition on Disabilities**
- *** Gift Certificate for FREE SHIPPING on next order** *** Only $24.95 per year**

Take advantage of this dynamic offer now! You can sign up any one of the following ways: CALL 800-535-1910 or Visit www.eparent.com & www.eplibrary.com

---

YES!! I want to join the EP Preferred Buyer Club so that I won't have to pay full price again!

Mail to: Exceptional Parent Dept: Membership P O Box 1807 Englewood Cliffs, NJ 07632-1207
Or Order on-line: www.eplibrary.com/epreferredbuyerclub/ Fax (201-947-9376 Or call 800-535-1910

Name: ______________________________
Address: ______________________________
City: ____________________ **State:** __________ **Zip Code:** __________
Telephone: ____________________ **Email:** ____________________

I have enclosed my check payable to Exceptional Parent or charge to my:

☐ **VISA** ☐ **Mastercard** ☐ **AMEX** ☐ **Discover**

Account Number: _ _ _ _-_ _ _ _-_ _ _ _-_ _ _ _ , **Exp. Date:** ___/___ **Signature:**

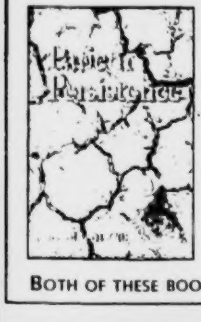
No Apologies For Ritalin ◦ BY VIDYA BHUSHAN GUPTA, MD ◦ EP8012AD- $19.95

Despite its name, No Apologies for Ritalin is aimed at educating parents of children with ADD by presenting all the treatments available for the disorder.

The first half of the book is a look at what ADD is: the medical aspects, how it is diagnosed, and what causes it. Anecdotes of children diagnosed with the disorder and a discussion of how doctors arrive at their diagnoses begin the book. Issues that parents must deal with, such as understanding and coming to grips with the diagnosis of ADD, whether ADD is a product of bad parenting style, ADD's occurrence with other disorders, and who is most at risk are discussed in this section as well.

Section 2 presents the pros and cons of all treatment options, both conventional and alternative, including non drug therapies such as psychotherapy and behavior modification. The author, Vidya Bhushan Gupta, MD, MPH, FAAP, writes in his Foreword, "I have discussed the controversy surrounding the use of Ritalin and tried to dispel myths surrounding ADD and Ritalin: 'ADD is not a disease; it is simply a difference of temperament;' 'ADD is due to poor parenting;' 'Ritalin is a mind-altering drug like speed;' 'Don't give Ritalin to your children because they will get hooked on it.'" He explains that his purpose for writing the book is so that "parents of children with ADD will not blame themselves for their child's predicament and will be able to use all the available treatments, including Ritalin, without guilt."

The book offers insights into other issues regarding ADD as well, including: who should treat the disorder and what the goals of that treatment should be; suggestions for parents on dealing with their child's ADD; whether children grow out of their ADD; and how to de-emphasize the negative labels of the disorder by recognizing and building on the strengths of children diagnosed with it.



Patient Persistence ◦ BY ADELE M. GILL ◦ EP8004GN-$19.95

Patient Persistence celebrates the ability of people to overcome obstacles to achieve their goals. Author Adele Gill invited individuals from every background to tell their stories of "hope, courage, hard work, and endurance related to health, disability, relationships, family, ministry, career, accomplishment and challenge."

Ms. Gill is a certified disability analyst/fellow with the American Board of Disability Analysts, and an advocate of inspirational/motivational self-help. She writes, "Patience and persistence are qualities that are vital to the discovery of our finest, God-given gift, the resilient 'Indelible Human Spirit.' These innate qualities propel people and enable them to do great things and overcome significant hurdles."

Patient Persistence is both motivational and inspirational, offering help and hope to anyone who feels that his or her life is out of control, or that things have gotten so bad that there will never be a way to make it better.

BOTH OF THESE BOOKS ARE AVAILABLE THROUGH THE EP LIBRARY BY CALLING 1-800-535-1910, OR BY VISITING THE WEBSITE AT WWW. EPLIBRARY.COM

Family & Community

BACK TOWARD NORMAL: HOW OUR FAMILY RECOVERED AFTER ALISON WAS BORN

By Genevieve Anton

I'll guarantee that every parent, at some point between the thrill of conception and the anxiety of the delivery room, has experienced the same fear: What if something is wrong with my baby?

Most of us like to think we would do anything, make any sacrifice, for our children. But when the vague fear you have tried to stifle becomes a reality, when your child is born with a severe physical or mental disability that threatens your own freedom and lifestyle, that commitment is put to the test.

After you have experienced the shock, the denial, the grief, it slowly begins to dawn on you. Your life has changed forever, in ways you never expected, never wanted, never dared to imagine.

I know. It happened to me.

My husband, Mike, and I were journalists in our mid-30s living in Denver when we first felt "the fear." We were far from our families, and ready to start our own. But our worries quickly dissolved when our son, Christopher, was born. He was absolutely perfect: healthy, strong, bright and adorable.

So four years later, when Alison was but a flutter inside me, we weren't quite as nervous. Our family history was clean. The amniocentesis, a test for chromosomal abnormalities, was normal. The pregnancy was going smoothly.

However, things went awry in my third trimester. I developed what is called polyhydramnios, or excess amniotic fluid that stretched my uterus so painfully I was put on half-day bed rest. Although my obstetrician tried to reassure us it wasn't necessarily a sign of trouble with the baby, the fear again bubbled to the surface.

Our attitude improved when I reached full term. Although we had an emergency C-section after 12 hours of labor, Alison was born at a robust 8 pounds with flawless skin, a full head of light brown hair and a delicate mouth shaped like a rosebud.

Her toes, I noticed, were a little crooked. That's all.

Still, we watched her closely. There was this nagging sense we weren't out of the woods yet. She slept an awful lot - up to 20 hours a day - and like a newborn puppy, couldn't seem to open her eyes. Alison would not latch to the breast, and often choked on the bottle of pumped breast milk. Her breathing was loud and raspy. She lost weight.

My pediatrician saw her once a week. He, too, assured us nothing terrible was wrong. Some babies just don't breastfeed, are noisy breathers and sleep a lot, he said.

It wasn't until I took the children to visit my family in Atlanta when Alison was seven weeks old that everything came crashing down. Fast. Hard. Unexpected.

"Just make it go away." At first, we thought it was allergies - that the little pollens wafting around in the humid Southern air had caused her respiratory attack. But the moment my sister's pediatrician saw Alison, he sent her to the emergency room and she was immediately admitted.

It was bad, and it would get worse. Her oxygen level was dangerously low, she was sucking milk into her lungs and her muscles were extremely weak, or hypotonic. Alison stayed in the Atlanta children's hospital for two weeks on oxygen and an IV, with a tube threaded through her nose to bypass her lungs and put milk in her stomach.

A parade of specialists examined her, took copious notes, huddled in the hallway. Radiologists scanned her brain and made X-rays of her body. Lab technicians took samples of everything - her blood, her urine, her mucus, her sweat - to run diagnostic tests.

No one could tell us

Mike, Genevieve, Chrostopher & Alison Anton at Golden Gate Bridge in San Francisco.

what, exactly, was wrong with Alison.

My mother says she vividly remembers finding me sitting cross-legged in the guest room, putting her arms around me and saying, "Is there anything I can do?"

"Just make it go away," I whispered.

Alison needed surgery to insert a tube into her stomach so she could eat, and a constant supply of oxygen. The doctors ordered a private medical transport plane to take us back to our home in Denver for the operation.

I cried the whole way home. I had never in my life felt such a deep, painful depression. For the first time since the crisis began, I started thinking about the future. Would Alison live? If she did, what would her life be like? And, to be honest, would taking care of child with chronic medical and developmental problems destroy our lives?

There were four of us - a nurse, a respiratory therapist, an emergency medical technician and myself - wedged into a cramped cabin with Alison strapped to a gurney in the middle. I watched silently, helplessly as they monitored her vital signs. She was so still and quiet. Her small chest was wired with electrodes, an IV bag swayed above her head and a tube in her nose pushed puffs of oxygen into her lungs.

My grief was intensified by a growing sense of claustrophobia in that airborne cage. I felt trapped and sick to my stomach. I was about to lose something vital and irreplaceable: not just the daughter of my dreams, but the essence of my life as I knew it.

My mind was flooded with thoughts about everything that would change. To take care of Alison, I would have to quit my job, cutting our income in half, and pull my son out of preschool.

I wondered if Mike and I would ever go out to dinner again, much less take a vacation alone. I thought about how much we love to travel abroad, to ski and hike in the mountains, to find hidden hot springs or alpine lakes, to explore new places. About the simple luxury of a good night's rest without being rudely awakened - and thrown into panic - by the ear-shattering beep of an apnea monitor.

These thoughts seemed so selfish. I felt guilty.

But ironically, it was the determination of our family to restore some sense of normalcy to our lives that helped us survive. It also changed our attitudes about what was possible for Alison, and brought her snugly into our warm fold.

Only later did I realize my feelings were not ignoble, nor unusual.

It's OK to feel selfish - and a little scared. Among the mountain of books on special needs children I've read over the past two years, there is usually a chapter on how it changes the family dynamic. The repeated physical and emotional crises. The canceled plans and ruined schedules. The financial burden of medical bills. The unrelenting pressure of caring for the child's needs.

"Finding out that your child has special needs is an emotional earthquake. Everything seems broke, turned upside down," writes Judith Loseff Lavin in her book, *Special Kids Need Special Parents*.

Extreme disappointment is inevitable, she says, as are questions such as, "What are we going to do?" or "How will we go on?"

"Parents often contact a myriad of specialists, hoping to find one who will tell them what they want to hear - that somehow life will go back to normal," writes Dr. Stanley Greenspan in the book, *The Child With Special Needs: Encouraging Intellectual and Emotional Growth*. Once they realize that's not going to happen, both parents may become terrified - terrified of their new life, terrified their marriage may fall apart, terrified they won't be able to handle whatever comes next.

Every family faces unique challenges and changes in life, but these are magnified for the family of a child with

continued on page 30

continued from page 29

a disability, according to Dr. Mark Batshaw, director of the Children's Research Institute, in his book *Children with Disabilities*.

"How the family handles day-to-day stresses, concerns and needs of its members influences, to a great extent, the outcome of the (special needs) child," he writes.

It was certainly the biggest change, and challenge, our family had encountered. At first, Mike and I were overwhelmed and confused, unsure how we would fare. People used to tell us we had been "chosen" to take care of Alison, because somehow we were special. But we didn't want to be special; we wanted to be normal.

Breaking free of the paralysis, our journey back toward normalcy began in an unexpected way. When Alison was four months old, my husband was offered a job at The Los Angeles Times. At the time, it seemed too soon to move. Alison was weak...we were exhausted. But it was a good job with better pay. And we hoped that leaving "The Mile-High City" to live at sea level might help Alison breathe easier.

It was a bold move, one that would force us to break out of our newly narrow - yet already familiar - existence. It would pitch us together and fling us across 1,000 miles to a different life. It would test our spirit and resolve.

First we had to cross the Rocky Mountains. We drove two cars and I insisted on taking Alison, along with her oxygen tanks and equipment. As we reached the top of the Continental Divide at almost 12,000 feet in altitude, she began to gasp. I startled at the shrill screech and red warning light of the pulse oximeter on the seat beside me. The oxygen content in her blood quickly dropped from 95 percent (good) to 88 percent (risky) toward the 70s (really bad.)

I pulled over to check on Alison, and watched in dismay as Mike's taillights faded away into the night. She had to get to a lower altitude fast, so I turned up her oxygen, hopped back in the car and speeded down the winding curves of interstate 70, feeling like an ambulance driver and thinking all the while, "This is crazy. What are we doing?"

Thankfully, Mike had pulled over at the first exit to

Your Family's Freedom is Here:

The Rear Entry Kneelvan.

The whole family fits: Kneelvan seats up to 7 people.

Scooters and chairs that won't fit in other vans can fit in a Kneelvan.

Kneelvan is the most reliable lowered floor minivan ever.

More ground clearance than any other lowered floor minivan.

Kneelvan's rear entry design can park anywhere, even in regular parking spots.

Designed with your family in mind, the **Kneelvan is simply the easiest way to travel**. Unlike side-entry conversions, we designed the rear entry KneelVan so you can **never get blocked by someone parking next to you**. Kneelvan is perfect for families with kids: its the best family van ever.

We would like to invite you to compare Kneelvan for yourself. Call today for more information and our free video.

Call Toll Free: 1-888-625-6335.

Freedom Motors USA Inc. "Our Quality is Your Freedom."

On the web at: www.freedommotors.com

Circle #30 or visit www.eparent.com/adinfo

wait for us and Alison began to breathe much easier in the valley below. We forged on, shaken but resolute.

Daylight and flat land in Utah brought hope and relief. Alison recovered nicely and stayed well the rest of the trip. She cooed happily in the car, sat patiently as we ate at restaurants (unlike her brother) and gamely went along in her stroller or my arms as we began to venture out and explore the barren beauty of the canyon lands.

As the 10-day trip continued, we became more adventurous. We took the Subaru off-road in Navajo country. We climbed up rocks and into shallow caves around Monument Valley. We hiked along the South Rim of the Grand Canyon National Park and watched the sunset from an isolated ledge with the kids on our laps.

Christopher & Alison

Everyone was surprised at how much we could do with Alison along, as long as we kept her comfortable and the hikes short. We stopped more often than normal, for her tube feeds and medication. Every night we set up her crib, pump and tanks in the hotel room like a miniature ER, with Christopher happily curled up on the floor beside her in a sleeping bag.

Alison was a real trooper, a good-natured baby who smiled a lot and hardly complained at all. She just loved being around us all the time, whether in the car or on a trail or wedged into a 10- x 20-foot converted garage of a friend in Long Beach, where we stayed for six weeks until we bought our home.

This was not the fragile baby on the plane; Alison had stamina and resilience.

The adventure recharged us, and the experience of living in such close contact for three months strengthened our bond with Alison. She was now one of us, and we could no longer imagine what it had been like without her.

Life goes on...and you must go with it.

Once we settled into our new home in Tustin, we began to venture out more often than we had once thought possible. Over the past year, we have driven more than 1,400 miles across California from San Francisco to San Diego to campgrounds and hiking trails across the Sierra Nevada Mountain Range.

We invested in an extra-sturdy baby backpack for hiking, a three-wheeled baby jogger for off-road exploration and a small pop-up tent to shelter Alison from the sun. Because she had so little strength in her body, especially her neck, we rigged an infant seat into Christopher's old Burley trailer so we could take family bike rides.

Of course, we also took every precaution for Alison's health, and packed plenty of medications, extra oxygen and emergency supplies.

Life was starting to get better, but it was not free of problems. There was the time Alison suffered a respiratory attack halfway into a hike in Mammoth Lakes. And after that, an eight-hour ride home in the early morning hours when she got sick on a trip to Yosemite National Park. We even had to leave a weekend camp for special needs children last summer when Alison couldn't keep down her formula.

Yes, there have been canceled vacations, delayed holiday celebrations and missed nights out. We plan our lives around Alison's illnesses, and she is sick a lot. Last year she was hospitalized eight times with various respiratory problems. She also had heart surgery to close two open valves, not to mention a slew of new diagnostic tests and more than 50 office visits to her pediatrician and more than a dozen specialists.

I grew so weary of answering the seemingly simple question, "So, tell me about Alison..." that I wrote a 16-page summary of her medical and development history that I update every month and hand out to hospitals, doctors and therapists.

Genevieve & Alison at Lake Tahoe

Some doctors suspect Alison suffers from a neuromuscular disorder that contributes to her chronic health problems and severe developmental delays. Yet so far her unusual condition has defied diagnosis, and her prognosis is still unclear.

Simple milestones, such as crawling or eating a Cheerio or saying "mama," are still beyond her reach at two years of age. Although Alison is making progress every day, we don't know whether she will catch up or simply fall further behind.

Even when Alison is well, she attends physical, occupational and oral/speech therapy sessions six times a week. On top of all that, there are untold hours of boiling medical tubes, filling prescriptions, reordering equipment and dealing with a stack of insurance claims that is already five inches thick.

As daunting as this

continued on page 32

Family & Community

continued from page 31

sounds, there are parents out there who face even greater challenges. I've seen children in the hospital who are immobile, unresponsive or heavily dependent on medical support to survive. I know parents whose children have severe emotional or behavioral problems that drain their patience and test their love.

But if we've learned anything through all this, it's that attitude is more important than circumstance. You can't always control what happens to you, but you can decide how you'll react to it. Our aim is to find a balance between Alison's needs and our own, and somehow make it all fit together as a family.

Dreaming new dreams. Life is hardly "back to normal" now and it probably never will be. Yet it isn't the nightmare we once imagined.

I don't pretend it's easy, or that we've been the perfect parents. Yet, as strange as it seems, there is a certain sense of pride that we've come this far. We changed, we grew and we found an inner strength we never knew existed. It certainly wasn't a path we wanted to go down, and the end is not yet in sight.

But we've finally started living our lives again - and our children are right there beside us, all the way. **EP**

Genevieve Anton of Tustin, CA, is a freelance writer with 20 years of experience in television and print journalism whose work has appeared in more than a dozen national and regional publications.

SURVIVAL TIPS FOR TRAVEL WITH SPECIAL NEEDS KIDS

- Get a quick checkup with your pediatrician before heading out of town, and ask what precautions you should take.
- Make a list of all your child's critical medical information, including history, prescriptions, allergies and the pediatrician's office and home phone number. Carry it with you everywhere you go, even on a hike.
- Find a hospital, pediatrician and medical equipment provider close to your destination. Check with your insurance company to see who's in network, how much is covered and what you need to do if your child gets sick out of town.
- Pack plenty of your child's medications, emergency supplies and any equipment that might be difficult to obtain without a prescription.
- Carry a mobile phone, emergency first-aid supplies and plenty of extra food and warm clothing with you in the car, on the trail or in remote areas.

HELPFUL WEBSITES

- The American College Of Emergency PHYSICIANS: Offers an Emergency Medical Sheet for children with special health needs that you can download from their website at www.acep.org.
- The Children With Disabilities: www.childrenwithdisabilities.ncjrs.org. Federal initiative to provide children with disabilities and their parents access to a wide range of resources including outdoor recreation.
- Comfort Connection: www.comfortconnection.org, 714.558.5400; toll free: 888.FRC.BABY. A place for parents of special needs children to make a connection with others involved in the enormous task of caring for a child who is born medically at risk or with a disability.
- Internet Resources for Special Children: http://www.irsc.org. A good starting point for information about outreach and resources for children with disabilities.
- The National Information Center for Children and Youth with Disabilities: www.kidsource.com/NICHCY. 800.695.0285 (Voice/TT), 202.884.8200 (Voice/TT). NICHCY is an information and referral center that provides information on all disabilities and disability-related issues as well as referrals to a wide network of specialized organizations and agencies across the country.

BOOK LIST

"SPECIAL KIDS NEED SPECIAL PARENTS"
A Resource for Parents of Children With Special Needs," Judith Loseff Lavin; The Berkley Publishing Group, New York, N.Y., 2001.

"THE CHILD WITH SPECIAL NEEDS"
Encouraging Intellectual and Emotional Growth," Dr. Stanley Greenspan and Serena Wieder; Persens Books, Reading, Mass., 1998.

"RAISING A CHILD WITH A NEUROMUSCULAR DISORDER: A GUIDE FOR PARENTS, GRANDPARENTS, FRIENDS, AND PROFESSIONALS"
Dr. Charlotte Thompson; Oxford University Press, New York/Oxford, 1999.

"CHILDREN WITH DISABILITIES"
4th Edition, Mark L. Batshaw; Paul H. Brookes Publishing Company, 1997.

LAWYERS INCORPORATED, P.C.

AND
AFFILIATED LAW FIRMS

Affiliated Attorneys
Nationwide

1-800-888-LAWS
www.lawyersincorporated.com

PREVENTABLE
DISABILITIES!

Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

You may be entitled to lifetime benefits.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

Circle #36 or visit www.eparent.com/adinfo

Family & Community

FAMILIES TELL US: What makes families STRONG

Beginning in the late 1980s, a new emphasis began to appear in research about the families of children with disabilities. This new perspective focused on how families succeed and used words like strengths, coping, resilience and empowerment.

What do these terms mean to families that include a child with a disability? We know that families are the real experts on this topic, so we turned to them to learn more. The goal of our research was two-fold. First, we wanted to learn, from the families themselves, about the strengths that they value most. And second, we wanted to alert professionals to these strengths, so that they could both acknowledge them and help families to build on them. One parent who talked with us made it clear why this is so important:

"Seventeen years ago, when our daughter was diagnosed, nobody told us any strengths. It was all like, 'Well, this is going to be really horrible for the rest of your life ...' [But] it can be a good experience, and we would do it all over again. Her brother had more responsibility than he needed to have because I needed somebody who could take phone messages when he was six years old. I thought at the time, 'Maybe this really sucks and I'm screwing up his life.' In fact, it has turned out totally the other way."

FAMILIES DESCRIBE THEIR STRENGTHS

This study was carried out by staff at the Center for Disabilities and Development, a component of the University of Iowa Hospitals and Clinics in Iowa City, Iowa. We provide health care and other services for people with disabilities and for their families. We asked each family:

- What are your strengths?
- How do you account for them?
- What strengths does your child with a disability bring to your family?
- What factors outside your family help nurture your strengths?
- How has your family changed as the result of having a child with a disability?

Each of the 38 families we talked with had been using services at the Center for at least a year. Their insights provided a clear perspective on what they see as the sources of their strength. Their answers identified six key factors: teamwork, family support, patience, hard work, adaptability and spiritual strength.

TEAMWORK

Teamwork, within the family and with people outside the family, is a primary source of strength. Within the family, both single parents and married couples tell us it is essential. "We are strong in hugs, and thanking each other, and asking each other for help when needed," says one parent. And families take pride in this strength: "We are incredibly bonded and dedicated to each other. We're tested more, but my husband and I have come through."

Brothers and sisters are also key members of the team. "If we both happened to be down," one family tells us, "the kids would say, 'We can get through this together.'" A mother speaking of her 11-year-old son says, "In the past he had said, 'I wish I had a regular brother, I wish I had someone to play with,' and there are really some hard, sad things said like that.

But over the years he's been such a support, and he'll help in any way that we ask. I'm pleased at the qualities I see in him." A father says, "We pretty much rally together to meet our child's needs—and each other's."

FAMILY SUPPORT

Families often speak of the strength that grows out of family support. This includes the bonds among siblings and grandparents, and those that single-parent families especially, share with aunts, uncles, and grandparents. One mother summed up this support very simply as "knowing I am not alone."

Making time for the family is one way to nurture this strength. "We always share the day's activities at dinner. We practice really hearing our children, what they have to say," says one parent. Another comments, "We work hard to be supportive of all our children." The support that families get from friends is also a source of strength. For example, "I have a couple of good friends who support me by getting me out of the house," says one young parent. "And they reassure me that I'm doing fine; they provide me with a positive outlook." Another parent comments, "We have learned to access support groups—other parents are the best help."

PATIENCE

Families tell us that patience, with yourself and others, is crucial. "You have to be strong, you have to laugh over things," says one mother. "We take it day by day. We had strengths before, but we are much closer as a family now." Another suggests, "Believe that things will work out over time." One mother says that she has learned to "let the little things go, both physically and emotionally."

HARD WORK

Plain old hard work is also key. A single mother describes herself as "a workhorse," holding down two jobs and still enjoying the time she can spend with her son. Another single mother says that one of her strengths is simply her ability to keep going every day. A father talks about his family's work ethic, and says, "We try to lead by example." A mother comments, "She needs more taking care of, and love, but there isn't anything wrong with that."

ADAPTABILITY

Families tell us that flexibility is important. Several parents reflect on how they have become more aware, more knowledgeable, and more assertive as a result of talking with others and learning to network. Another says, "We have a better perspective now on what's a big thing, what's a small thing."

"We've gone through so many trainings, and we've learned not to accept the word no," says one mother. "And from 'no integration,' today [our daughter] is mainstreamed 55 percent of the time." Another credits her husband's self-help reading, and describes his creativity in making their home more accessible.

Recalling the first sign language class she attended, one parent remembers that there were "cousins and aunts and uncles and nephews, grandmas and grandpas, that went to the signing class to learn how to sign. You know, I always wanted to learn a different language, but I never would have learned sign language before, and it's really become a positive thing in our life and our family."

STRENGTHS OF THE SPIRIT

Many families find strength in their faith in God. "I don't find answers," says one mother, "but I do find peace." Others cite such strengths of the spirit as compassion, tolerance, a sense of humor and being slower to judge others. "Our values haven't changed so much as deepened," says another parent. "You know you can't put yourself first anymore," one parent explains. "Now I'm a fighter, for all of them, and this gives my life meaning."

Families tell us that children with disabilities contribute to their families in many ways—through their sense of humor, happiness, cheerfulness, patience and courage. One mother talks about how many friends her son has: "People like him all over town." Several talk about their child's strength of will in getting through medical crises and overcoming things, and others com-

continued on page 36

continued from page 35

ment on their child's plain determination. "He is a hard worker," says one, while another asserts, "My son is alive today because he's stubborn and determined."

Love and admiration are common themes: "She's strong in the face of pain and fear," says one mother. "Sometimes I think she's almost too strong. She is so large in such a little body." A single mother says, "I came close to giving him up for adoption; it all looked too overwhelming at first. But now there is joy and peace in simple things. It doesn't take a whole lot to find happiness. I don't know—how can you describe intangible things? He grounds you. I don't understand why I'm his mom; other people would be better at it than me. But then I think, 'Nobody can love him like me.'"

HOW DO WE PUT WHAT WE'VE LEARNED TO WORK?

Every family has strengths that make it special. Recognizing, acknowledging and building on these strengths make a family stronger. Too often, though, families and professionals alike focus on problems or concerns, and neglect to acknowledge the strengths a family can call upon. As a result, families may feel unnecessarily overwhelmed.

Families have so much to teach us—and each other. As professionals, we are learning to listen better, so that we can help families come to understand the traits that make them strong. Together, families and professionals can find solutions that reflect, and tap, these strengths. Clearly, they are a powerful resource, one that should be acknowledged, nurtured, called upon — and celebrated. EP

Sally Darley, LMSW, is a family therapist at her private practice, Bowland-Duarte and Darley Counseling Services. She specializes in play therapy with children, creative therapies with adolesence and positive approaches to parenting.

Jim Porter, MSW, LISW, has been a social worker for the past 16 years at the Center for Disabilities and Development in Iowa City, Iowa.

John Werner, LMSW, is a social worker at the Center for Disabilities and Development.

Susan Eberly, MA, wrote the article with the help of Sally, Jim, and John; she has been a writer and editor at the Center for Disabilities and Development since 1984.

Offering New Hope for Children with Cerebral Palsy and Brain Injury

Ocean Hyperbaric Neurologic Center

Richard A. Neubauer, M.D., Medical Director

Since 1972, we have been committed to providing the finest outpatient treatment available using hyperbaric oxygen therapy. Dr. Richard A. Neubauer has dedicated himself to the ethical expansion of hyperbaric oxygen therapy for severe neurological conditions. Specializing in cerebral palsy and the brain injured child, he has successfully treated the following:

- **stroke**
- **closed head injuries**
- **near drownings**
- **multiple sclerosis**
- **chokings**
- **shaken baby syndrome**
- **carbon monoxide poisoning**

Dr. Richard A. Neubauer and the Ocean Hyperbaric Neurologic Center are pleased to announce:

The 3rd International Symposium on Hyperbaric Oxygen in Cerebral Palsy and the Brain Injured Child

Richard A. Neubauer, M.D.,
Symposium Director

July 16-19, 2003
Fort Lauderdale, Florida

For information on the upcoming Symposium, call
(800) 552-0255
or email
symposium@oceanhbo.com

(800) 552-0255
• Call for free video & information

For more information, visit
www.oceanhbo.com
Email info@oceanhbo.com

4001 Ocean Drive
Lauderdale-by-the Sea, Florida

EP neither endorses nor denies the effectiveness of hyperbaric oxygen therapy. For Editor-in-Chief statement see our Contents page.

Circle #40 or visit www.eparent.com/ad info

NOT JUST LOVING PETS

Dogs Improve Quality of Life

By Laura Apel

Above: Sunni Foty, 8, from Minnesota getting help from her canine companion Roan.

Left: Haley Eidsen, 8, with her mother Cindy Eidsen and their just graduated Skilled Companion Dog, Zeb.

All a dog truly knows is love. Spend time with one. Look into their eyes. The love encompasses. They live for their people, would do anything to protect their loved ones and never ask for anything in return. They just love.

Assistance dogs, those specifically and expertly trained to assist people with disabilities, are perhaps the most dedicated and devoted of all. They become the eyes, ears, bodies, minds, and best friends of those they pride themselves in serving. Assistance dogs save lives.

These animals are raised to become the constant companions of adults and children with special needs. They are trained with the capabilities of picking up objects, turning off light switches, guiding through traffic and alerting after specific sounds.

Most Assistance Dogs have one universal skill in common that outshines and far exceeds all of their physical capabilities. These dogs bring love, attention, devotion, confidence, and belonging to their human partners that many have never before experienced.

Assistance dogs bridge the gap that exists between those with and without disabilities. They decrease the helplessness and the sense of loneliness that these individuals so often feel and enable them to take part in social activities that they had previously been prevented from joining.

continued on page 38

continued from page 37

Canine Companions for Independence (CCI), is the oldest and largest non-profit provider of assistance dogs for people with disabilities. Since 1975 CCI has been recognized for its excellence in placing their extremely qualified dogs with the people that they can best serve.

Matt and Lenora Thompson with their dog Odyssey.

Temperament, desire to please, social nature and adaptability are the key elements of the selection process in determining which dogs are best suited for particular jobs. CCI assistance dogs are one of three types of canines: Labrador Retrievers, Golden Retrievers, or a cross of these two breeds.

There are two parts to the training process. For six months each assistance dog undergoes a minimum of six months training with a professional CCI Instructor and then completes a two-week Team-Training with their future human partner.

These dogs are never aggressive or noisy, never have "accidents" in public and take their work very seriously. *A good example can be witnessed through Levi the dog in the new series F.B.Eye (see sidebar).* Each CCI dog has passed or exceeded the level of training that is required to earn public access under state and federal laws, including the Americans with Disabilities Act.

CCI Assistance dogs are trained to serve the needs of those with all different forms of disabilities. There are four categories that the dogs are placed, trained, and later partnered in.

Service Dogs. These dogs are trained to work with an adult who is disabled but who has the physical ability to work independently with a canine. Service dogs are matched with people of all different lifestyles and occupations and are trained to perform specific tasks that are designed to enhance the independence of their part-

Puppy Love

By Ann Allen

Heroes. We've heard this word in the news a great deal recently, and for good reason. They're all around us. Firefighters, police officers, rescue workers, Red Cross volunteers. The list is endless really. Our family recently encountered more people to add to the list. I'm referring to the people involved with the non-profit organization, Canine Companions for Independence.

My son, Eric, was recently the lucky recipient of one such companion. Eric's gentle dog is a beautiful two-year-old female who is a cross between a golden retriever and lab. Her name is Bethany and she weaseled her way into our hearts approximately 48 hours after learning of her existence. When she looks at Eric with her expressive brown eyes and he awkwardly leans his body into hers, I feel they were meant for each other. She gracefully licks him to redirect the occasional harsh strokes that Eric delivers, and does so with the patience of a new mother with her child.

For several years now we have watched our eight-year-old son Eric interact with dogs. Although Eric's special needs have left him severely physically and cognitively delayed, the reaction towards Eric that we've seen elicited from some of our friends' dogs is unique. We have watched several different dogs lay next to Eric in an unusually protective way, as if they can sense his vulnerability.

As we saw these interactions repeatedly occur we debated whether we should get a dog. We hesitated for all the typical reasons that you might guess. What would we do with the dog when we went on vacation? What about all that dog hair in the house? Dogs jump on people. Dogs bark and chase squirrels.

Well…right now, this very minute…Bethany is lying in Eric's room "hanging out" with him. You see, she's the only one in the family that has time to do just that. My husband is working, my daughter is cleaning her room, and I'm pretending to be a writer. Don't get me wrong; we love spending time with Eric. It's just that the demands of life keep us very busy. It's comforting to know that Eric has a big, warm, furry body there to nuzzle up to when he feels like it. Bethany allows him to be Eric. She doesn't mind that he makes loud noises, or that his body won't let him move the way he wants it to move. She doesn't care that he drools sometimes and that his touch can be kind of rough. But I think she does sense that his heart is kind, gentle and pure—just like hers, and that he would never hurt her. This gift came from the people at CCI.

It's impossible for me to describe the day in which placements occurred. Eight nervous families were standing in the training arena waiting to be placed with their dogs. Although CCI instructors repeatedly remind you not to get emotionally attached to a particular dog, it was impossible for me not to do so. To be honest, I loved Bethany so much by the second day, I felt I was losing my objectivity and begged for a different dog. I couldn't sleep at night without dreaming about dogs. And trust me, I was not a dog person.

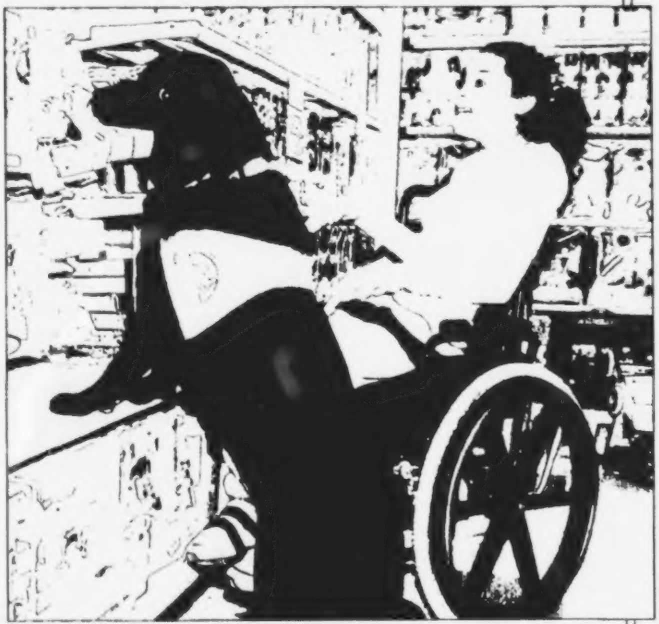
Before placements occurred, we were alerted that other people might be joining us that day. It was true. There are many people who are involved with this organization who love to see the moment when the dogs are placed with their recipients. CCI employees came out of their offices, financial donors came to watch, as did puppy raisers, and even one of CCI's veterinarians. When Bethany was placed with Eric, tears spilled from my eyes. Not only was I grateful to our exceptional instructors, but I realized that the grace of Bethany was the joint effort of many outstanding individuals.

Bethany had been born and bred in California, placed with loving puppy raisers, then shipped to Ohio for advanced training with her outstanding dog trainer. She then was placed with our severely handicapped child. What a gift of love Bethany is. She is a product of the culminated efforts of so many good-hearted individuals. Those individuals will probably never realize what good work they do, or how their efforts positively affect so many individuals who can't always express what their hearts are feeling. But I know, as a parent of a "special" child, that their efforts mean the world to one little boy…our son, Eric.

ner. Service dogs will pull their partner in a manual wheelchair, flip light switches, push buttons for elevators, open refrigerators, retrieve dropped objects, and assist with business transactions by referring money, receipts and packages. Service dogs perform the tasks that enable their partners to experience the independence of having a trained canine perform jobs that had previously been done by other people. They aid in the quality of life of their human partners.

Hearing Dogs. These dogs work with adults who are deaf or hard of hearing and are trained to alert their partners to particular sounds by making physical contact with them. The ring of a doorbell, cry of a baby, knock at the door, alarm clock, intruder, call of a name and smoke alarm are all sounds that will trigger a response in the dogs. These hearing dogs bring a sense of security and confidence to the human partners they protect.

Facility Dogs. What separates these dogs from the others is the fact that they are not permanently placed with a special needs person. Facility dogs are trained to work with a facilitator-handler who is able-bodied and who works or volunteers in settings such as hospitals, extended care facilities, physical therapy programs, hospices, special education classrooms, and programs for people with developmental disabilities. These dogs offer patients opportunities for physical activity, as in throwing a ball for the dog or building strength in grooming sessions. These dogs, in their companionship, unconditional love and attention, give these patients added motivation to participate actively in their recovery process.



Allison and her dog Twilight make a great team.

Skilled Companion Dog. These dogs are trained to work with an

continued on page 40

Assistance Dog Goes Hollywood

Sue Thomas and her hearing-ear dog Levi are solving crimes and hooking viewers on Pax TV's new show "Sue Thomas: F.B.Eye."

Based on the true-life story of Sue Thomas, the show follows her experiences with the FBI in Washington, D.C. The opening episode begins as Sue, who has been deaf since early childhood, leaves her parents' home in Ohio for the first time to begin her new life and career for the Bureau. She stops and picks up her hearing-eye dog Levi along her way and the two immediately bond.

Sue soon impresses her co-workers with her ability to read lips and is quickly promoted to a position where her skills are used to crack crimes in places where listening devices can not penetrate. Levi is her constant companion and best friend who aids and supports her through every case.

Sue Thomas herself is extremely pleased with the direction that the show has taken. As she explains, "this series is making history. It is the first to bring these worlds together on television in such a powerful and positive way." The show is groundbreaking as never before has there been a television series that was based on deafness with an actor who was deaf.

However, F.B.Eye is not the only television series depicting a challenged character this season. Daryl "Chill" Mitchell, who had a recent accident that placed him in a wheelchair, is a series regular on "Ed;" Marlee Matlin, who is deaf, has a recurring role on "The West Wing," and many other people with disabilities are being featured on television in the growing willingness of the business to portray these individuals.

Sue Thomas also mentioned her happiness in the depiction of Levi. She explains, "you couldn't tell my story without having Levi- he's my ears!" The real life crime-fighter went further to comment on her definite approval of the golden retriever chosen to be her friend Levi; Jesse. "Jesse, the golden retriever who portrays Levi, is everything I could ask for and more…take a look into those eyes and you'll find the love, trust, and security of your best friend. I look forward to the day when I am no longer asked that common question, "What's a hearing dog-what do they do?"

Sue Thomas F.B.Eye airs Sundays at 9:00-10:00p.m. (ET/PT) (CC).

continued from page 39

adult or a child with a disability as well as a second individual. This second individual is most often a caregiver, spouse, or parent who serves as the facilitator in handling and caring for the assistance dog. Both the recipient and the facilitator attend the two-week Team Training session. Like service dogs, Skilled Companion Dogs perform tasks that their disabled partner can not. They are helpful in a great number of tasks that are common to every day living.

Dogs have been documented to have saved the lives of humans on physical and emotional levels throughout time. They are our eternal and unconditional best friends. Assistance dogs reach further because they are needed in a larger sense. Adults and children with disabilities could and do survive without them, but many are realizing the reasons why they don't need to. EP

HDIS

Convenient Home Delivery of Bladder Control Products

Try our *Reassure*. Protective Underwear

FREE Sample Offer!

Available in Size Small!

- Low-Rise style.
- Cloth-like material pulls on and off like regular underwear.
- Locks away moisture and neutralizes odors without using fragrances.
- Sides tear away for easy removal

Available in: Small (22-29" waist/hip), Medium (26-40" waist/hip) and Large (36-56" waist/hip)

Call now for a FREE sample!

1-800-2MY-HOME®

(1-800-269-4663)

"We're happy to answer any questions you have."

- Mary

All HDIS products are delivered direct to your doorstep in discreet boxes. Call our friendly, knowledgeable Customer Care Representatives today!

©2002, HDIS 024-136

Circle #32 or visit www.eparent.com/adinfo

CCI Locations

National Headquarters &
Northwest Regional Center
PO Box 446
Santa Rosa, CA 95402-0446
(707) 577-1700 Voice
(707) 577-1756 TDD

North Central
Regional Center
4989 State Route 37 East
Delaware, OH 43015-9682
(740) 548-4447 Voice/TDD

Chicago
Satellite Office
PO Box 41
Woodstock, IL 60098
(847) 816-7360 Voice

Northeast
Regional Center
PO Box 205
Farmingdale, NY 11735-0205
(516) 694-6938 Voice/TDD

Southeast
Regional Center
PO Box 547511
Orlando, FL 32854-7511
(407) 834-2555 Voice

Southwest
Regional Center
PO Box 4568
Oceanside, CA 92052-4568
(760) 754-3300 Voice

Colorado
Satellite Office
1045-P Garden of the Gods Rd
Colorado Springs, CO 80907
(719) 260-6151 Voice

Or visit their website at
www.caninecompanions.org

For additional Service Dog
resources and organizations
visit www.wolfpacks.com
for a complete directory.

College Bound

When Brandon first came to Heartspring School, his goals were simple: learn to ride a bike, improve gross motor skills, and control aggressive behaviors. Now he has bigger ideas: bowling, computers, tennis, golf ... and choosing a college. Yes, Brandon will graduate from high school this May and embark on an extraordinary new stage in his life. Goes to show what's possible with the right kind of help—even when you have Asperger's Syndrome.

HEARTSPRING™
SCHOOL
Finding New Ways for Learning
8700 East 29th Street North · Wichita, Kansas 67226
call 1-800-835-1043
www.heartspring.org

Circle #18 or visit www.eparent.com/adinfo

1369

Family & Community

FAMILY DYNAMICS

IN THE TREATMENT OF TOURETTE SYNDROME

Lynne Rosen, CSW

While there have been great scientific advances made in the treatment of Tourette Syndrome (TS), including better medications that target the most debilitating symptoms, many children suffering from this disorder must still deal with the daily onslaught of teasing and ridicule from their peers.

People are often both intrigued and horrified when witnessing the stream of strange sounds and movements associated with TS. Educating the public can have tremendous value by lessening the stigma. However, all the education in the world provides little comfort to a child who comes home from school demoralized and defeated, not knowing how to best handle peer reaction that ranges from curiosity at best to cruel taunting and ostracism at worst. Therapy can help children to respond more effectively to their peers. When children take charge of the situation, their sense of identity and resolve is strengthened resulting in a surge of self-esteem.

For all children, self-esteem stems from successfully mastering developmental challenges and taking new initiatives, and requires energy to do so. However, children with TS must contend with both internal and external forces beyond what their peers must face. They may expend endless amounts of energy not only on suppressing their tics in the presence of others, but also on struggling to develop a positive self image in the face of negative feedback from their environment.

These children do not have to passively absorb such negative feedback. This is where the family can play a major role by helping the child to fight against those detrimental forces that threaten to undermine his stability.

Good therapy should be geared toward helping children and their families to view TS in a different light. Rather than seeing it as a "punishment" or a "handicap," it can be seen as an opportunity to tackle a difficult challenge, that when mastered, results in the development of a more solid sense of self. This hard-earned competence comes from knowing that the child has overcome a major personal life obstacle. Ultimately, it can fuel determination to succeed no matter what further obstacles lie ahead.

Although Tourette Syndrome poses major challenges to a child's functioning, it can also serve to mask underlying conflicts in the family that may have lingered for years. Parents who seek treatment for a child with TS may become fixated on the child's distressing symptoms while ignoring other significant issues. Therefore it is important for the therapist to carefully assess whether TS is indeed the main problem or whether it may be conveniently camouflaging painful conflicts in the family.

If the latter is the case, then at the outset of treatment, the therapist must begin to sift through the complex family dynamics and determine where there are openings to make positive, new changes. The goal is to foster a gradual shift away from the exclusive focus on TS and toward a deeper understanding of how family members may be interacting in harmful and destructive ways. I have found that this often results in a reduction of TS symptoms as well as a strengthening of the family's foundation.

One particular case comes to mind of an eleven-year-old girl I'll call Lydia. Lydia had been recently diagnosed with TS, and was beginning to reckon with uncontrollable eye blinking and high pitched barking noises that escaped from her mouth during her classes at school. At those moments, tense laughter permeated the room and Lydia desperately wanted to disappear. She often found refuge in the girl's bathroom where she would stare at herself in the mirror wondering why this awful thing was happening to her and not the other kids. Despite her winning, charming personality and careful attention to her appearance, Lydia began to see herself as a "total misfit."

Lydia's mother had already read much literature on the topic and had a fairly good grasp on the fact that this was a neurological disorder in which the severity of the symptoms fluctuated over time. While she sincerely encouraged Lydia to overcome the negative effects of her condition by achieving new goals, part of her was mired in anger over seeing her daughter as being stuck with a condition that was out of her control.

> DURING ONE PARTICULAR SESSION WITH LYDIA I SEIZED UPON AN OPPORTUNITY TO BREAK THE DEADLOCK. LYDIA PLOPPED DOWN ON THE CHAIR AND STARED AT ME SULLENLY FOR SEVERAL MOMENTS. WHEN I ASKED HER WHAT WAS WRONG, SHE GAZED UP AT ME WITH HER PIERCING BLUE EYES AND SAID "MS. ROSEN, WHY CAN'T I JUST BE NORMAL?"

The key word here is "control." We know that children cannot completely control their tics anymore than their parents can control all the hostile reactions from the world. However, this does not have to lead to the sense of helplessness and futility to which Lydia's mother had become a prisoner. In sessions, while she intellectually spoke about the ways in which Lydia could better manage her TS, she emotionally was a wreck. She spent many sleepless nights imagining Lydia's future; one dominated by frustration and hardship over all the unfair treatment that she would experience. She also had periods where she would lapse into self-pity thinking "why did this happen to my child?" This behavior is strikingly similar to what Lydia displayed in the girl's bathroom at school.

Children model ways of functioning and coping from their parents. Unfortunately, some modeling can be destructive to a child's well being. Once these destructive patterns have become firmly established, they can chip away at all the positive strides children with TS attempt to make to combat their condition. The therapist can help the family to identify and get a grip on these negative patterns and eliminate them from their repertoire of functioning.

On one hand, Lydia's mother made sure that Lydia was involved in extra-curricular activities. She never hesitated to drive Lydia to her music lessons and other activities and encourage her to stick with them. As a result, Lydia began standing out from her peers and winning competitions. Yet the problem was that she was unable to experience the full glory of these accomplishments because of the self-defeating behavior she had adopted from her mother. This left her vulnerable to outside attacks that tore away at the good feeling she had worked so hard to build up.

The final blow came during a math exam at school. Lydia had been working vigorously to raise her "B+" average in math to an "A." Math had become her obsession. It was almost as if acing this exam would be another symbolic victory over her TS. It is important to continually encourage these children to fight against discrimination with achievement. However, as Lydia began to dissect the difficult equations, she grew increasingly nervous. With

continued on page 44

Family & Community

continued from page 43

each stroke of the pen, her tics grew louder, until finally one of her classmates jumped up from this seat saying "can you shut the hell up already, you freak!" Lydia fled the classroom in tears. When her teacher ran out to the hall to console her Lydia dropped to the floor and shouted "There's no point...why do I bother trying?"

Following this incident, both mother and daughter fell into a funk. Waves of negativity filled my office for the next several sessions. At that point, I stepped in as the voice of reason by compassionately but firmly pointing out to Lydia's mother that TS was not to blame for all of Lydia's problems. While the therapist must certainly empathize with the unique challenges the TS child faces, she must also help the child and other family members if necessary to develop a "thicker skin" when it comes to facing their own difficulties unrelated to TS.

In Lydia's case, mother and daughter had become deadlocked. They were embroiled in a highly reactive, volatile pattern of relating where both repeatedly fed on the other's insecurities. Their collective strengths were not surfacing, but instead had become swallowed up by a mixture of emotions that included guilt, sadness and anger. I want to note that these feelings were not only connected to TS, but also stemmed from the mother's ineffective handling of her own lifelong struggle with low self-esteem. She had been attempting to bolster her esteem by being a good parent. While this was a step in the right direction, when anything outside of her "control" (i.e. TS) interfered with her efforts, she felt crushed and overwhelmed.

During one particular session with Lydia I seized upon an opportunity to break the deadlock. Lydia plopped down on the chair and stared at me sullenly for several moments. When I asked her what was wrong, she gazed up at me with her piercing blue eyes and said "Ms. Rosen, why can't I just be normal?"

I told Lydia that she might have this condition for the rest of her life, but that it did not have to stop her from living. Lydia immediately responded in a desperate voice, "But that boy called me a freak."

I then asked her if she really believed she was a freak. Lydia hesitated a moment and then calmly said, "No... but."

"But what?" I interrupted.

"But my mom cries a lot about it," Lydia said.

When I asked her how she felt when her mother does that, she said, "Mad...I just want her to stop." I then asked her if she ever told her mother to stop.

"No, because she seems so sad," she responded.

And when I asked Lydia if she thought that was because of her, she twisted her hair nervously and replied with a "no." I then told Lydia it did not matter how the other kids reacted to her tics as long as she strove for her best. She smiled as she left my office.

The following week her mother requested to see me individually. She told me that she realized it was not only Lydia who needed help. She then related how one day Lydia came home from school and told her that the same boy from the test had picked on her for her condition again. But the story continued when Lydia said, "Don't worry mommy...I told him to shut up and worry more about failing math," as soon as she saw her mother begin to get upset. Her mom began to sob, saying, "I wish I had half the self-esteem Lydia has."

I pointed out to her that she could begin to build real self-esteem by managing her emotions better and finding new ways to fuel her own self-confidence. This session marked an important turning point for the family, one in which a mother finally took responsibility for herself. Once Lydia stood up to her tormentor, her mother could no longer use TS as a reason for not facing her own psychological issues.

During our final sessions, much tension eased between Lydia and her mother. Of course, sometimes there still are arguments that center on Lydia's growing independence. However, mother and daughter had begun to feed more off of each other's energy. Lydia was now more prepared to weather any teasing that came her way. Treatment ended on both with a note of optimism and caution. I reminded Lydia's mother that while she had taken a positive step, this was only the beginning and that she needed to work on improving herself, otherwise she would not be able to keep up with Lydia's progress. She told me she understood this and had decided to seek individual therapy to support her with the changes that she needed to make.

This case demonstrates the value of insight oriented therapy in addressing the effects of TS from an individual, family and social perspective. It can lead to more effective management of TS symptoms as well as greater self-confidence and a sense of resolve. **EP**

Lynne Rosen is a New York based psychotherapist, writer and consultant. The Tourette Syndrome Association provides counseling to residents of New York City. For more information or an appointment please call the Queens office at (718) 224-2999 or the Brooklyn office at (718) 858-5985.

Family & Community

SIGNING FOR SUCCESS

By Abbey Woodard

Bradley Woodard signing "Mommy".

For most parents, your child's first word is an extremely joyful time in your life. He is finally changing from a baby into a little person, who is capable of expressing his wants and needs, and later his thoughts and feelings. But if your child has a speech delay this potentially joyful time can be an extremely sad and frustrating ordeal. Instead of a child who is happily babbling and uttering the occasional spoken word, you have a frustrated toddler who screams and cries because he cannot understand why you do not know that he wants something as simple as juice instead of milk.

I have been in this situation. I have a son, Bradley, who has Down syndrome and has a speech delay because of this diagnosis. Due to a developmental speech delay that children with Down syndrome have, and other problems such as low muscle tone, he was unable to talk when other children his age began speaking. This was an extremely difficult time in both of our lives. Bradley was frustrated because he could not tell what he wanted, and I was frustrated because it seemed that all he did was scream. Then one day at a therapy session, Bradley's speech therapist suggested teaching him signs.

Having learned sign language as a child, because of a friend with hearing impairment, I was immediately receptive to the idea. I started out with teaching Bradley one sign "eat." I figured that this was a crucial sign that would help ease some of his frustration. Every time I spoke the word "eat" while Bradley was sitting in his highchair, I would also use the sign. The first few times I did this he looked at me as if I were crazy, then in a few weeks he started catching on. Then one joyous day, when he was throwing one of his temper tantrums, I asked him what he wanted and he stopped, wiped the tears from his eyes, and signed, "eat." I was delighted! My baby could talk!

With the word "eat" having

continued on page 46

Abbie Woodard with her son Bradley, who uses sign language to communicate.

continued from page 45

been mastered, I began to teach him other simple signs that he would need to communicate such as "drink," "cookie," "night-night" etc. Before long, Bradley was learning signs in no time. Now at the age of three, he has a signing vocabulary that consists of over 200 signs. His signs include everything from different types of foods to names of animals to even colors. This child who, at one time spent much of his time screaming and crying, was now pointing out pictures in books and showing me the signs.

One of my first questions to my son's speech pathologist was does the use of signs initially instead of words delay speech? The answer to that question is "No." The use of signs only allows a child that is not talking an avenue to express himself. My son is now at the point that he will try to speak a word and if I do not understand him, he will then use his sign as backup.

Sign language books for children can be purchased at a local bookstore or checked out at a local library. I recommend a children's sign language book opposed to an American Sign Language dictionary because a children's sign language book will have signs more often used by children, whereas an American Sign Language dictionary is more complex and contains many signs and a structure of signing that you will not use.

Due to emerging fine motor skills in young children, the signs that children produce may sometimes vary from the original sign. This is fine. Your child is not trying to become an interpreter of American Sign Language. He is simply trying to communicate. Any sign that he shall make and use consistently to mean a certain thing will be fine. As long as you, and the others involved in his life understand him, the goal is achieved.

The use of sign language will not correct your child's inability to talk but it will tremendously ease the frustration of not being able to communicate. The key element in this process is patience. In the beginning, it takes some time for your child to "catch on" to what you are doing. It also takes repetition. But I guarantee you that the time and patience spent using this technique with your child will, in the long run, make the quality of life during those first tedious non-talking months or years better for the both of you. EP

Sign Language Resources:

Gallaudet University Bookstore
1-800-451-1073
Sign Language Coloring Books
Sign Language Interpreters and Interpreting
Sign With Me Books
TJ Publishers
1-800-999-1168
Signing: How to Speak with Your Hands
Talking Hands: A Sign Launguage Video for Children
http://www.bn.com
Lesson Tutor
http://www.lessontutor.com
Honey the Signing Teddy Bear *http://www.quiet-bear.com*

Abbie Woodard is currently an undergraduate honors student in the School of Communication Disorders at Florida State University in Tallahassee, Florida. She is presently researching and writing a senior honors thesis on using sign language with children who are developmentally delayed. She plans on receiving her Master's degree in Speech and Language Pathology.

EARLY INTERVENTION SERVICES:

A FAMILY-PROFESSIONAL PARTNERSHIP

Family & Community

By Carolyn Cantu, MS, OTR

"Your child may experience developmental delays." The shock of hearing that prognosis from the neonatologist or pediatrician is numbing. Some parents receive this news at the birth of their child, along with a diagnosis. Some notice milestones are not being met as their child develops. Either way, the initial trauma and emotional adjustment create sometimes-overwhelming feelings of guilt, anger, blame and depression. Questions race through parents' minds as they grapple with "What are we to expect? How can we help now? How will we ever afford the cost of treatments?" and most important, "Who will help us?"

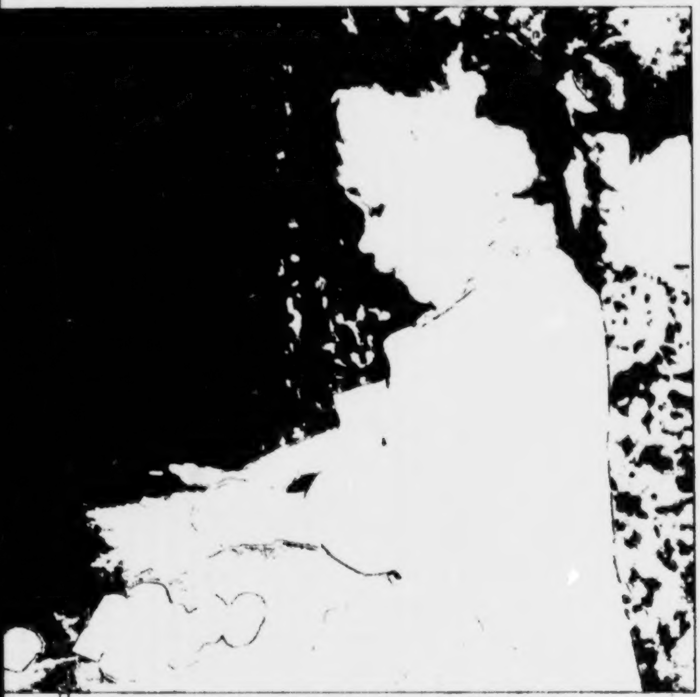
Help for children and their families does exist, through early intervention programs nationwide. Early intervention programs are devoted to enhancing development, minimizing developmental delays and providing instruction, support and assistance to those children and their families. This commitment is ongoing.

HISTORY OF EARLY INTERVENTION PROGRAMS

The Education for All Handicapped Children Act of 1975 initiated the course of action for early intervention programs and future legislation. By 1986, Congress established the Part H program for infants (aged zero to two years) and toddlers (aged three to five years). The legislation was considered momentous because it promised to provide services to all young children and their families. Research compiled by the mid 1980's strengthened the proposal considerably, suggesting significant progress in young children with disabilities who had received early intervention services. Cost-effectiveness figures were impressive enough to extend "free and appropriate education" to three- to five-year olds with disabilities. The states were now required to designate the most appropriate agency to determine services for that young population.

Gradually, as the legislation was applied nationwide, attention began to transfer from the individual child toward care of the child and family receiving care. Consequently, an

continued on page 48



Showing bilateral integration, this little girl uses both sides of her body to engage in coloring her box with chalk.

continued from page 47

inclusive, holistic approach was implemented in early childhood programs across the country, requiring fourteen components within each state system. Part H defined developmental delays, delineated eligibility and required execution of a multi-disciplinary evaluation of each eligible child, development of an individualized plan of intervention for the child and the family and a timetable to ensure services. The integrated approach toward child and family care was well underway.

Additional legislation honed these concepts. In 1997, Part C of the Individuals with Disabilities Education Act (IDEA '97) focused on the services provided for young children with disabilities. Congress stipulated that there was an "urgent and substantial need to enhance the development of infants and toddlers with disabilities and minimize their potential for developmental delay." It is in Part C that "services are required to be provided in the child's natural environment to the maximum extent possible." The law went on to emphasize the role of families in intervention "to enhance the capacity of families and the special needs of their infants and toddlers with disabilities." Developmental areas of concern and qualified personnel are clearly defined.

FAMILY CENTERED INTERVENTION

Although differences in names, service guidelines, policies and procedures occur state to state, early intervention service programs are presently designed to work in partnership with families. The purpose and practice is truly a collaboration of support and skills as parents and professionals work toward common goals. This is why families are considered a vital part of the Individual Family Service Plan (IFSP), for children aged zero to three years, then of the Individual Education Plan (IEP). These plans are the product of a cooperative effort between family and staff. Initially, the IFSP/IEP states the child's present level of functioning, parents' priorities, concerns, and the family's resources.

Based on assessment results, goals are set by families with guidance from the professional team, which may include therapists, teachers, social services and early-childhood specialists. During the development of the IFSP/IEP, parents or guardians actively participate in establishing priorities, goals and strategies to develop their child's strengths and minimize their limitations.

"What do you want to see your child doing at this stage?" may be a typical question to parents. Usually, achieving developmental advances is of primary importance. At this point in the process, a realistic time frame is usually established. It is at this planning meeting that additional needs of the family are also discussed: perhaps they need assistance with establishing respite care, or with time management, or exploring local day care. The IFSP/IEP covers all those needs and concerns by establishing a set of strategies to address each issue.

Setting goals and strategies is not enough in this holistic approach to family care. In 1993 Brown, Thurman and Pearl, in Family Centered Intervention with Infants and Toddlers, addressed the importance of considering the variety of family units as vital in reaching successful intervention. Early childhood professionals make every effort to demonstrate sensitivity to racial, ethnic and cultural diversities. Personnel typically honor these differences in their approach to every single family. The personalities of parents and siblings are also seriously considered. Reactions, strengths and limitations of each family member influence the expectations each has of one another. Understanding and using the varied ways of coping may enhance the child's progress.

The pivotal element of family-centered care is the recognition that the family is constant and the intervention setting is temporary. The role of the early intervention provider is to support, teach, and assist the family in promoting life skills and reducing delays. Family members are the hour-to-hour, day-to-day therapists and teachers. They reinforce language, behavior training, feeding, positioning, sensory input, and movement techniques. They read with their children, build from blocks with them, match colors, sort and encourage language. They are the most important, consistent people in their child's life and are most responsible for their child's progress.

Because parents and other family members are so important in the execution of the individualized plan, early intervention programs strive to accommodate the family's home environment, community and schedule as much as possible. It is not uncommon for a therapist to visit the child in the home with the family one week and at the day-care center with its staff the next.

In this way, both family and day-care providers benefit from the therapist's instruction, demonstration and suggestions. One reinforces the other and the child benefits from intervention no matter where s/he is during the day. The professional intervention team will be a part of the family's life for up to three years. Eventually, however, the child moves on. At three years old s/he is off to another early childhood program. The professionals who work with the child change but the family remains constant.

ECI: FROM REFERRAL TO TRANSITION

Initial awareness of a local program usually comes from the family physician, pediatrician, neurologist or hospital staff, or a family member may do research on the state's Early Childhood Programs or Early Childhood Intervention Service websites. Parents, family members, physicians or clinics may refer a child to a local program. There is no waiting list. Most, though not all, programs stipulate that the child must be seen within 45 days of the referral call. Each program has its own progression. Generally, after the initial screening/intake, a team of professionals—either an OT or PT, a teacher, speech pathologist, nutritionist and social worker—executes a formal assessment.

This assessment and future service take place in the child's "most natural environment to the maximum extent appropriate," that is, the place where the child spends most of the day. This may be the child's home, the home of a caregiver or a day-care center. When the child turns three years old, s/he "graduates" to the next-level program. This might be a school district's early childhood center, a day-care center, a private preschool, private therapy or continued care at home until legal school age.

Part C of IDEA lists the qualified personnel of the intervention team: special educators, speech and language pathologists, audiologists, occupational and physical therapists, social workers, nurses, nutritionists, family therapists, orientation and mobility specialists and pediatricians and other physicians. Licensed, certified professionals and paraprofessionals staff early intervention programs. All specialize in the development of young children. These are the

continued on page 50

Resource List and Bibliography

Brown, Wesley, PhD, Thurman, Kenneth S., PhD, Pearl, Lynda F., PhD, Family Centered Early Intervention with Infants and Toddlers. Innovative Cross Disciplinary Approaches. Brookes Publishing Co. Baltimore, MD 1993. ISBN 155766124-3

Council for Exceptional Children, 1110 North Glebe Rd, Ste 300, Arlington, VA 22201-5204
Tel: 1-888-cecsped or http://www.cec.sped.org

Families and Advocates Partnership for Education (FAPE) http://www.fape.org.

House Education and Workforce Committee. http://eduworkforce.house.gov

IDEA97 Part C Infants and Toddlers: http://www.ideapractices.org

National Association for the Education of Young Children (NAEYC) http://www.naeyc.org.

National Early Childhood Technical Assistance (NECTAC) http://www.nectac.org
Campus Box 8040, University of North Carolina, Chapel Hill, NC 27599-8040.
Tel: (919) 962-2001. Email: nectac@unc.edu

National Information Center for Children and Youth with Disabilities (NICHCY).
Email: nichcy@aed.org

Office of Special Education and Rehabilitation Services (OSERS): "23rd Annual Report to Congress on the Implementation of the IDEA" http://www.ed.gov.osers
Office of Special Education Providers (OSEP) http://www.ed.gov/offices/OSERS/OSEP

Shonkoff, Jack P. and Meisels, Samuel J. Eds, Handbook of Early Childhood Intervention. Second Edition, Cambridge University Press, 2001. ISBN 0521585732

Family & Community

continued from page 49

individuals who provide assessment, intervention, reassessment and transition services for the child until his/her third birthday.

HOW PROGRAMS ARE FUNDED

As stated in IDEA '97, funds for assessments and visits by the early intervention staff come from the state and federal governments, with grant money as possible supplemental funding; thus, there is no cost to individual families. Private insurance may be billed if the family so wishes, and ECI programs are required to bill Medicaid and CHIP for services.

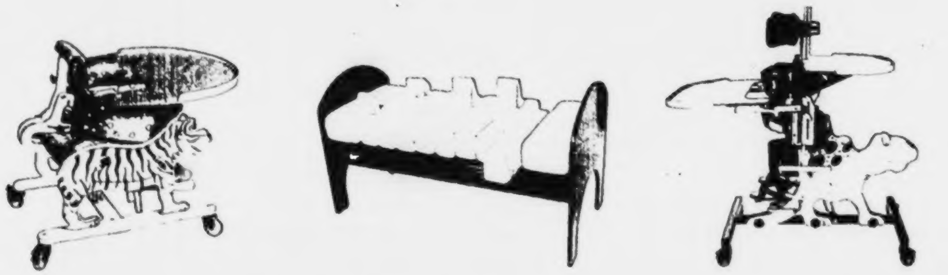
NEW LEGISLATION

There is reason to expect that the 2003 Reauthorization of IDEA will reinforce the collaboration of families and professionals. It is not a new concept that when children are diagnosed with disabilities or developmental delays, they depend on family for more support. Families are the first and most constant source of nurture, strength, help and education for their children, especially those with special needs.

Monumental as it is, the task facing families is shared by early intervention service programs. These programs strive to achieve common goals with their family partners while maintaining a high standard of care. Parents first learning of their child's developmental delays will find help by connecting with their state early intervention service. That initial communication will put the family in contact with their local program and intervention will begin at no cost. Legally sanctioned, these programs impart appropriate intervention to developing infants and young children while providing attention, support, and education to their families. EP

Carolyn O. Cantu, MS, OTR, is a licensed pediatric ocucpational therapist and educator who has practiced and taught all over the world for 32 years. Most recently, she was a pediatric therapist and clinical educator for the Infant Parent Program, Austin, TX.

525,600 minutes a year. Now a child can be properly positioned for every one of them.



With the Jenx™ Animal Collection for daytime therapeutic positioning, and their Dreama™ Sleep System for night, Bodypoint Designs brings perfect positioning to the whole body...24/7/365.

JENX

Distributed by BP BODYPOINT® DESIGNS
800-547-5716 | www.bodypoint.com
558 First Avenue S., Suite 300 | Seattle, WA 98104
In Canada, call Advanced Health Care Products, Tel: 800-265-9830

Circle #20 or visit www.eparent.com/ad info

1378

A PEDIATRICIAN'S TREATMENT FOR HER DAUGHTER

PART 2 • BY JO FEINGOLD, MD

In the November 2002 issue of EP, Dr. Feingold talked about her five children. Elisa is her second child and was born with a neurological disorder that caused significant developmental delays. Despite the multiple therapies she received, Elisa's condition showed little improvement. When a relative suggested that Elisa might benefit from hyperbaric oxygenation therapy (HBOT) Dr. Feingold disdained it. In her own opinion and that of neurologists she consulted, HBOT therapy for CP and related disorders was considered to be quackery. This article explains how and why Dr. Feingold changed her mind and became an HBOT supporter.

The hardest thing about having a child with special needs is being able to be a mother to all my children without having any of them resent Elisa for being different and still being able to provide for her as if she were an only child.

HYPERBARIC OXYGEN THERAPY

Three years later, when I started to network with other families, I heard of a study about hyperbaric oxygen therapy going on at Cornell University Medical School and enrolled my daughter. She received her first 40 treatments in December 1999. Now, my physician training comes into play. I am acutely cognizant of all the theories..."the placebo effect"..."the positive reinforcement of having your parents in the chamber with you"...etc., etc. While Elisa was being treated, I felt as if she was waking up. She was able to say about 35 words then. She was not toilet trained. She was unable to watch any children's TV programs. She said "mik" when she was thirsty and screamed when she was hungry.

The first major change I saw occurred during the first week of treatments. She turned to me and said "booscoos." I had no idea what she was trying to say. The mother who was in the chamber with me said that she thought Elisa wanted to watch "Blue's Clues." I told her that Elisa didn't watch tapes; she told me her son was watching it earlier, so maybe Elisa had seen it. We put the tape on and my daughter remained glued to the monitor for the next 45 minutes. I was the highly trained physician, the one with all the knowledge. How little I knew!

Over the next few weeks Elisa started to talk. Three months later in the supermarket, I realized she was naming everything she saw. Almost instantly I realized that I was wrong; I wasn't doing everything I could for my daughter. I took a second mortgage on my house and bought a hyperbaric oxygen chamber so I could continue to treat Elisa close to home—and I could treat other children as well. Elisa has made incredible progress over these past two years. She is alert; she laughs and plays with her brothers and sisters and is otherwise a beautiful child.

About six months ago I decided to send my daughter to Hungary for conductive education at the Peto Institute. We needed to obtain a passport for her. We waited for hours in the waiting area. Elisa started talking to a woman who was going to France and waiting for her passport. I was shocked at how well Elisa was able to communicate with her. When the woman did not understand her, my daughter repeated herself and rephrased what she wanted to say until she was understood. I realized that although her little body is so spastic and unable to do what she wants, she has an incredible ability to communicate with people. She makes herself heard and understood. And that was the most important thing I could give her.

People tell me I was gutsy for putting everything we owned into the hyperbaric oxygen center we now operate. I say that I only did what any other mother would do. What I did was to ignore what my training had instilled in me and reverted to the Hippocratic Oath I took as a physician: to "first do no harm; then treat until treatments are no longer effective." I know that there are no valid randomized double-blind clinical trials that support the efficacy of hyperbaric oxygen therapy in people with cerebral palsy. I also have seen first-hand how patients improve from its use. Essentially, I saw something that worked for my child and did everything I could to make sure she had all that she needed to help her thrive and grow.

continued on page 52

> **...the most important lesson I learned...came from my first-born. She said "Don't you understand, mommy? We're all different on the outside but inside we are all made the same. Treat Elisa just like us."**

continued from page 51

The hardest thing about having a child with special needs is being able to be a mother to all my children without having any of them resent Elisa for being different and still being able to provide for her as if she were an only child. Some days I do better than others. I still have days in which I am depressed and fall into despair. There are the dark days in which I ask myself if it was too much to ask to have five normal children, and why did God give me this burden to bear? There are days in which I ask myself how long my strength will hold up, how long I will be able to carry her. But I realize that these are fleeting moments and wasteful self-pity. Most days I feel privileged to be a mother. I feel good about being able to provide HBOT therapy to others. I love to see children gradually change and grow.

I have learned to appreciate what it means to be the parent of a special needs child...because I never learned this in medical school. I never knew about chronic disabilities in medical school and all that I learned about them, I realized, I had learned from parents. I learn every day as a physician , but mostly as a mother. In fact, the most important lesson I learned did not come from a textbook; it came from my first-born. She complained that she thought that I was not treating all my children the same. I naturally thought that what she meant was that Elisa was getting preferential treatment—but I was wrong. She thought I was singling Elisa out. She said "Don't you understand, mommy? We're all different on the outside but inside we are all made the same. Treat Elisa just like us."

Sometimes if we keep our minds and hearts open and we listen carefully, our children can teach us much. I am a mother and a physician most richly blessed! EP

Adaptivemall.com™

Shop On-line!

Tim's daughter Carrie.. a young adult with Down Syndrome

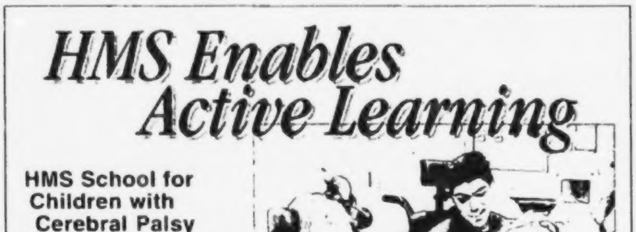
We Understand... Each child with special needs requires specific product solutions. www.adaptivemall.com offers you an easy way to explore quality brand names of adaptive positioning equipment............and OT/PT on-line SIZE HELP facilitates your selection.

Tim Bergeron has more than 25 years of experience as a product expert of special needs equipment. He is the founder and original designer of Tumble Forms®. And as the father of a child with a disability, he understands the challenges that you face. www.adaptivemall.com serves everyone with this concern in mind. Click and explore on-line or call us toll free 1-866-529-8407.

Tim Carrie !!

Tumble Forms is a trademark of Sammons Preston Copyright 2001 Bergeron Health Care

Circle #19 or visit www.eparent.com/ad info


HMS Enables Active Learning

HMS School for Children with Cerebral Palsy serves children, ages 2-21, who have multiple disabilities resulting from cerebral palsy or traumatic brain injury. Skilled, compassionate staff and consultants provide individualized inter-disciplinary programs that enable each child to flourish and learn.

Day & Residential Programs • Special Education
Physical & Occupational Therapies • Speech/Language Therapy
Music Therapy • Nursing & Nutrition Services • Medical Support
Therapeutic Recreation

State-of-the-Art Assistive Technology:
Augmentative/Alternative Communication
Computer Access
Environmental Control
Powered Mobility

For more information contact:
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy
- FOUNDED IN 1882 -
4400 Baltimore Ave., Philadelphia, PA 19104
215-222-2566 • Fax: 215-222-1889
www.hmsschool.org
E-Mail: admin@hmsschool.org

Member: NAPSEC • Pennsylvania's Alliance of Approved Private Schools

Circle #34 or visit www.eparent.com/ad info

Wraparound Mental Health Services

QUESTIONS AND ANSWERS

Stephen J. Bugaj, EdD, Randall L. Manning and Renee Brunner

While this article was written primarily for Pennsylvania residents, wraparound services are available in many states. Contact your state department of mental health for information in your area.

WHAT ARE WRAPAROUND SERVICES?

The term *wraparound* is used to designate several mental health (MH) services provided to children in their homes, school, or in the community. In essence, these services "wrap around" a child and help to avoid unnecessary out-of-home placements or hospitalization. Wraparound services have been available in Pennsylvania for some time, yet many parents have never heard of them and have no idea how to obtain them for their child.

WHAT SPECIFIC MENTAL HEALTH SERVICES ARE AVAILABLE THROUGH WRAPAROUND?

The wraparound mental health services used most frequently include therapeutic staff support (TSS), mobile therapy (MT) and behavioral specialist consultation (BSC).

Therapeutic staff support is one-on-one intervention by a trained person with a specific student in order to modify symptomatic behaviors. It might include crisis intervention, immediate behavioral reinforcement, re-direction, role-playing and consequence strategies. The purpose of TSS is to increase the sense of responsibility and age-appropriate behaviors of the student and to promote the student's problem-solving and self-sufficiency skills.

Mobile therapy is individual and family psychotherapy. However, the format for delivery of this service varies according to the individual needs of the student. Critical elements of mobile therapy include active listening, treatment planning and exchanging information with the student and family.

Behavioral specialist consultation involves assessment, program design and student monitoring, rather than direct therapy. A behavioral specialist designs a behavioral plan that incorporates non-aversive methods and can be implemented on-site by a TSS person.

WHAT ARE THE QUALIFICATIONS OF THE INDIVIDUALS WHO PROVIDE WRAPAROUND?

TSS people are required to have a bachelor's degree in a human-services field and training in crisis intervention. Other levels of education can be accepted contingent upon experience. Mobile therapists are licensed mental-health professionals or individuals with graduate degrees in mental health who have experience in implementing MH services. Behavioral specialists are often licensed doctoral-level psychologists or graduate-level clinicians skilled in behavior modification.

I LIVE IN RURAL PENNSYLVANIA. ARE THE SAME SERVICES AVAILABLE TO MY CHILD THAT MIGHT BE AVAILABLE ELSEWHERE?

Not necessarily. Wraparound is largely dependent on the number of local service providers and trained individuals available to provide the services. Consequently, rural areas may not have the same availability of wraparound as larger communities.

WHERE CAN THESE SERVICES BE PROVIDED? FOR EXAMPLE, WHAT IF MY CHILD NEEDS THEM WHILE HE IS IN SCHOOL?

Wraparound services can be provided in almost any setting where the child's behaviors are preventing normal functioning. In the public schools, TSS, MT and BSC are readily available. TSS may even be available on the school bus, should the student require it.

MUST I PAY FOR ANY OF THESE SERVICES?

No. Wraparound in Pennsylvania is covered by Medical Assistance (MA). As each child must have a mental health diagnosis to receive these services, s/he is eligible to receive an individual MA card regardless of parental income. The use of the MA card will not affect any insurance coverage that parents may have.

IS IT TRUE THAT WRAPAROUND SERVICES ARE BEING CUT AND PARENTAL INCOME IS GOING TO BE CONSIDERED BEFORE AUTHORIZING THEM?

No. While the Department of Public Welfare in Pennsylvania recently drafted a document suggesting these very changes, the Pennsylvania State Legislature passed a budget on June 2, 2002 that appears to have denied this income cap.

MUST MY CHILD HAVE AN IEP IN ORDER TO GET WRAPAROUND?

No. Wraparound services are available to more students than just those served by the special education system. While students identified as seri-

continued on page 54

continued from page 53

ously emotionally disturbed under IDEA are eligible to receive wraparound, so, too, are students who are at risk of developing emotional problems.

MUST MY CHILD BE LABELED IN ORDER TO GET THESE SERVICES?

No. The evaluation process and the criteria required for eligibility are less formalized with wraparound. A psycho-educational evaluation of the student is not required; rather, a psychiatrist or licensed psychologist must recommend that the services are medically necessary for the student, and the Child and Adolescent Service System Program (CASSP) team must determine that the services are required.

EXACTLY HOW DO I GO ABOUT GETTING WRAPAROUND FOR MY CHILD? IS THERE MUCH RED TAPE INVOLVED?

All requests for wraparound services must go through the CASSP team. Under the direction of a CASSP coordinator, an interagency team of parents, community agencies, local service providers and school personnel develops an individual treatment plan that authorizes MH services for a designated period of time for a specific child.

DO I HAVE ANY SAY IN DETERMINING THE SELECTION OF SERVICES FOR MY CHILD?

Absolutely. Parents are full participants in the CASSP process. In fact, the CASSP team may not even proceed unless the parent attends the meeting. Parents also have the final choice of local service provider should several be available. On the negative side, students who are 14 years of age and older may legitimately refuse to take part in these services regardless of the recommendations of the CASSP team or the wishes of the parent.

WHAT IF MY CHILD NEEDS MORE THAN ONE WRAPAROUND SERVICE?

Depending on the needs of the child, several wraparound services might be implemented. For example, it is common for a student to receive TSS at school and MT at home.

HOW SOON AFTER THE CASSP MEETING CAN I EXPECT THESE SERVICES TO BEGIN?

It depends. As noted above, the availability of wraparound is often contingent upon having trained individuals to provide the service. Consequently, there may be delays of several weeks or longer between the CASSP Team meeting and the actual delivery of the service. Typically, TSS takes the longest time because the state must review each case and authorize services prior to their provision. If staff is available, TSS should be provided within 60 days from the date of the request.

WHAT IF THERE ARE DELAYS IN GETTING THESE SERVICES STARTED?

In areas served by more than one service provider, delays in beginning wraparound may be addressed by selecting the provider who has trained staff available. Should delays occur in delivering TSS in the school, the CASSP Team may consider asking the school district to assign a teacher aide to the child on a temporary basis and only until wraparound begins. Such a consideration must be done with full cooperation of the local school district.

As MT and BSC do not require prior authorization from the state, these services can begin almost immediately. Should delays be encountered in implementing TSS, MTs and/or BSs can assist the teacher aide in providing interventions until a regular TSS is assigned.

HOW LONG MAY MY CHILD RECEIVE THESE SERVICES?

One of the main components of wraparound is to transfer these skills to parents, teachers and other caregivers so that children can be maintained in their natural settings without the presence of wraparound staff. So, unlike special education and related services made available under IDEA, wraparound is designed to be of short duration and may only be available for an abbreviated period of time.

WHAT HAPPENS IF MY CHILD STILL NEEDS THESE SERVICES AND THEY ARE NO LONGER AVAILABLE? OR WHAT IF THE CASSP TEAM DETERMINES MY CHILD IS NO LONGER CONSIDERED ELIGIBLE FOR WRAPAROUND?

Routinely, the child is re-evaluated every four months to determine if wraparound is still appropriate. Before the termination of any wraparound service, the service provider should reduce the frequency and length of sessions over a period of time to allow for behavioral improvements to occur in more normalized situations.

In situations where long-term assistance is required in the school and is not authorized by the service provider, the school district may again need to consider assigning a teacher aide or paraprofessional to the student. Before this occurs, it is important that the service provider and district ensure that the aide is properly trained to deliver the same type of MH services as was done previously by the TSS.

WHAT HAPPENS IF THESE SERVICES DON'T WORK? WHAT ELSE CAN BE DONE?

The CASSP Team should reconvene and address the child's needs. The current level of service might need to be increased, or additional wraparound services may be required.

WHAT IF I AM UNHAPPY WITH THESE SERVICES? WHAT ARE MY RIGHTS?

Medical Assistance suggests that parents share such concerns with the agency providing the service first. Should this step prove to be insufficient, parents should contact the county Mental Health Administrator. A phone number should be included as part of the paperwork related to the student's situation.

WHAT HELP MIGHT THERE BE SO THAT I CAN UNDERSTAND THE SYSTEM AND ACCESS WRAPAROUND FOR MY CHILD?

The local county Mental Health Office can provide parents with more information on wraparound and the CASSP Team process. Additional assistance may be obtained through intensive case management (ICM), which helps parents acquire needed medical, social and educational services for their children. ICM coordinates the delivery of these services for the family once they are obtained, and helps families access seven day/24 hour assistance in crisis situations. Ask the local Mental Health Office if ICM is available in the area. EP

Stephen J. Bugaj, D. Ed.
Superintendent
Cameron County School District
drsbugaj@yahoo.com
Randall L. Manning
Executive Director
Northwestern Human Services
Canal Ways Center
1301 Allegheny St, Ste 119
Hollidaysburg, PA 16648
Renee Brunner
BHRS Director
Northwestern Human Services

RESOURCES

Two articles that might provide additional information are: *Suggestions for Improving the Delivery of Therapeutic Staff Support in the Public Schools* (Bugaj & Manning), Journal of Mental Health Counseling, January, 2002; and *Linking Schools with Youth and Family Centers* (Bush & Wilson), Educational Leadership, 1997.

NEVER GIVE UP THE SEARCH TO FIND THE RIGHT PLACE...

"I was advised to settle for something less, but kept searching. When I visited Crotched Mountain there was a tangible difference in attitude– a professionalism, respect, and "can-do" attitude that set them apart. Standards are high and the approach genuine–they really care! I am very happy with Crotched Mountain and most importantly, so is my son Jared. He has grown enormously in many ways and is becoming the young man that I always thought he could become. It's a family's dream, come true!" —*Kathy Berns*

Crotched Mountain School
- Special Education, K-12
- Vocational services
- Day & Residential Programs

Children's Specialty Hospital
- Sub-acute rehabilitation
- Post-surgical care
- Respite services

Serving families since 1953

For more information, call **800-966-2672**
One Verney Drive, Greenfield, NH 03047
www.crotchedmountain.org
email: admissions@crotchedmountain.org

CROTCHED MOUNTAIN
OFFERING A LIFELONG ALLIANCE TO PEOPLE WITH DISABILITIES

Circle #23 or visit www.eparent.com/adinfo

A PARENTS DETERMINATION and a Pre-K Dream Realized

By Sherri H. Epstein & Ann G. Bessell, Ph.D.

"It's probably Cerebral Palsy," said the Early Intervention therapist. Rachel was only four months old during this initial evaluation. She couldn't hold her head up, roll over, sit-up, or crawl. She couldn't even lift her arms or legs. She had no eye contact, cried constantly, and never slept. I knew something was wrong and feared she would never bond with me.

I remember starting to cry. The grandmothers looked on, tried to hold back their tears, but they couldn't. My perfect child was officially not perfect. After collecting my thoughts and trying to shed the feeling of devastation, I tried to think of the positives. As long as it's CP, I thought this diagnosis meant that she would be physically disabled, but her mental faculties would be intact. We called to make an appointment with a neurologist within 10 minutes of the initial CP diagnosis. Unfortunately, two months passed before we could get an appointment.

When Rachel was six months old the neurologist ordered an MRI. He informed us that, "She has 'white matter disorder' and it is probably degenerative," although he wasn't at all certain exactly what it was. Now I was wishing it was "only CP." More tests were ordered and we didn't get an affirmative diagnosis until Rachel was eight months old. We now know Rachel has Canavan Disease; a genetic disorder she inherited from both Ken and I who each carry a mutated gene that caused Rachel to be born without an enzyme in her brain to neutralize the brain fluid. Because the fluid is so acidic, the myelin in Rachel's brain is deteriorating.

The doctor was only able to give us limited information so we searched the Internet for answers, hope and guidance. We learned that children with Canavan Disease continue to deteriorate, never roll-over, walk, or speak. They lose their eyesight and become mentally retarded. Their life expectancy is from one to four years. When we made contact with other parents of children with Canavan, we learned that some children live to be ten, and a few parents buried their children at age 20. Although we found little hope, we were determined that Rachel would live as full and happy a life as we could provide.

As we did more and more research, and after talking to many parents of children with Canavan, we have learned to question what we read rather than accept the grim limitations described in the literature. We have learned to just focus on what Rachel CAN do, not on what she can't do, or what she will become. It has been even harder to convince everyone else of that, as well.

Early Intervention (EI) services started right away. I asked Rachel's physical therapist (PT) to find out how we can get a stander. Her response was "Why bother?" I couldn't believe what I heard. If anyone needed to have a positive attitude regarding Rachel, it should be her PT. I immediately requested a new PT. The new one was amazing. She met Rachel and immediately began to do wonders with her. By the time Rachel was 14 months old, the crying stopped. She was reaching for toys and standing in her stander. At that point I realized that it is up to me not to give up on her and to fight for what I believe.

It took a great deal of time convincing EI that Rachel should work with a speech therapist while at a young age. Finally, after several months, someone was assigned to work with her. Rachel lit up every time the speech therapist came. She taught Rachel to choose a song from pictures and then sing. Well, she never actually could sing, but Rachel would light up, open her mouth and sounds began to come out. To think that they didn't want to assign a speech therapist to Rachel because she wouldn't be able to talk. Another "why bother" attitude. The Speech Therapist taught me to recognize Rachel's different sounds and to let Rachel know that I recognize what she wants by these sounds. Rachel looks so proud when I let her know that I understand what she wants.

When Rachel was two I asked the EI case manager about preschool. I knew that Early Intervention was coming to an end when Rachel turned three. The case manager told me that there wasn't anything I needed to do. "It's all automatic," she said. Then she added, "EI does the paperwork and at the Individual Education Plan (IEP) team meeting.

They will go over where Rachel will go to school." I thought that sounded too simple. Nothing in Rachel's life has been simple. I said that I wanted to see the school options before the meeting so I could have some input. She told me that Rachel would be placed in a special needs class in a special needs school, so there really wasn't anything more to see.

I went over to the school to see the classroom. It was a class of seven children in their wheelchairs. Due to their severe mental and physical disabilities, the children were not able to interact with each other. It was not a very stimulating environment. Their aides were socializing with each other, instead of working with the children. I was sick to my stomach. I did not want Rachel to go here. She is fully aware of everything and very cognizant. She needs to be constantly stimulated or she will be bored.

I would take Rachel to Jessica's preschool classroom occasionally. Jessica was always proud to show off her sister. She would bring her dolls and toys to play with and want to sit with her at "circle time" to hold her hand. Jessica's friends were also very receptive. They loved having Rachel come and visit. Rachel also attended "Play Group" through Early Intervention. She loved going. The teachers would always include Rachel in every activity: circle time, sitting at the table for snack time, being put in the sensory table, and piling her lap up with toys to help clean up and bring them to the closet. She loved the attention and being able to participate. I knew that the preschool we choose should be as active.

I started to interview everyone I knew who was involved in the public school system. Friends and family members who are school teachers and therapists all gave their input. The bottom line was to insist on what I believe was right for Rachel. They told me to expect nothing, but ask for the moon. Since the people who were going to decide where Rachel should go would not have the opportunity to meet Rachel, I prepared a photo album of her. There were pictures of Rachel in playgroup, singing, playing with the other kids, and over-heating from a 90-degree day. I had pictures of Rachel in her stander "talking"

continued on page 58

CINCINNATI HYPERBARICS

Hyperbaric Oxygen Therapy

"Your comfort and well-being are our prime concern"

Unique Alternative Approaches

Cincinnati Hyperbarics has a unique blend of both orthodox and alternative approaches.

State of the Art Equipment

This is a physician owned, operated, and staffed facility. Dr. Ted Cole works with each person to help maximize the benefits from their treatments at the center.

Exceptional Care

Dr. Ted Cole evaluates every patient. He designs and supervises every patient's course of therapy and monitors every patient's progress, and is able to provide other treatments to accelerate and enhance each person's recovery.

Cincinnati Hyperbarics - Phone (800) 667-5395 or (513) 563-4321 - Fax (513) 563-3131
www.cincinnatihyperbarics.com - info@cincinnatihyperbarics.com

EP neither endorses nor denies the effectiveness of hyperbaric oxygen therapy. For Editor-in-Chief statement see our Contents page.

Circle #47 or visit www.eparent.com/adinfo

continued from page 57

with her sister, as they looked at each other eye-to-eye. There were pictures of Rachel laughing while swinging on a supportive swing in a playground. I even included a family portrait taken while we were on a ferry (to prove that we include Rachel in everything we do). Basically every picture that I included reinforced my demands of what Rachel would need.

I then started the IEP Team meeting with the following statements:

"We acknowledge that Rachel has Canavan Disease, a degenerative neurological disorder that will ultimately take her life. We feel very strongly that this is the 'prime' of her life, and therefore want her to have the most that life has to offer, as long as she enjoys it, in the least restrictive environment.

She enjoys socializing with her peers, painting, coloring, looking through magazines and pictures, doing puzzles, playing with noisy toys, computer games and listening to music. We feel she will do best in an integrated classroom with "normal, healthy" peers.

In order for Rachel to actively participate in all of the activities that an integrated classroom has to offer, she will need a one-to-one aide. Although Rachel loves to paint, due to her low muscle tone, she needs help holding the paintbrush, etc."

The team leader seemed impressed. There were about 14 people at this meeting. I brought her EI case manager, physical and speech therapists, her vision therapist, a gentleman from the Commission for the Blind, and a family advocate who has helped me get Rachel, equipment that

Dreams for Rachel to be happy

To be told that your daughter will die by age four is devastating enough. However, the lack of hope for a cure doesn't change the dreams and desires Sherri and Ken have for Rachel to be happy. Not only has school energized and enhanced Rachel's life, in return she is also making an impact on everyone she interacts with. She is teaching the children in her class about compassion, tolerance, and understanding of others. Parents should not accept the limiting self-fulfilling prophecy of others (if we treat someone as if they can't do anything, they won't).

It is evident that Rachel is doing so well because her parents don't see her limitations, and don't let others give her any limitations. They have searched for options, considered all the alternatives, and have embraced a collaborative approach so the professionals who know Rachel best can participate in the educational decisions that will provide her with the best quality of life available. Rachel will be celebrating her 4th birthday this September and continues to laugh, thrive, and embrace life.

What to Look For When Considering a Preschool

1) The Program Basics and that Teachers/Staff provide a developmentally appropriate curriculum and have the willingness to make adjustments when necessary.

A. One-on-One aide who not only meets the child's personal needs, but also makes certain that the child is included in all activities (calls for flexibility and creative thinking).

B. Program allows for modification so a special child can participate in all activities.

2) Small group size and low child-to-teacher ratio (one-on-one aide can help create a small class environment).

3) Outdoor play

A. Nature walk, playground, etc. should be wheelchair accessible (sand on a playground makes it difficult to maneuver a wheelchair)

B. Toys in gym include toys that a child in a wheelchair can play with. Shaded area so child doesn't sit in direct sunlight.

4) Health and Hygiene:

A. Nurse available every minute of the day (including bus ride in case of seizure, choking, vomiting, etc. during the ride.)

B. Changing table for diapers should be convenient and private and also allow for tube feedings, medicine administration etc.

5) Indoor Physical Environment:

A. Supportive chair that is low to the floor for "circle time"

B. Activity table that allows wheelchair to fit at the table

6) Family Involvement:

A. Maintain a notebook filled out by PT, OT, Speech, Vision therapists, as well as teacher to explain daily activity and how the child tolerated activities. This must be done daily and consistently. (If the child is non-verbal, this is especially important since the child can't tell mom how her day was. Keeping the parents in the loop, helps keep the parents involved).

B. The centers willingness to have the parents visit and observe at any time.

Ann G. Bessell, Ph.D.
Research Assistant Professor, Department of Teaching and Learning, School of Education, University of Miami, Coral Gables, Florida.

Ann got her Ph.D. after her 12-year-old son, Jonathan, lost his battle with lymphoma. Her main goal is to improve the quality of life for children with health issues. Her research emphasizes the importance of collaborative communication among professionals and teaching teachers effective educational strategies to facilitate the learning and social needs of children with special needs. She can be reached at: Agbessell@miami.edu.

she needs (Pediasure, diapers, bath chair, etc.). We were ready for a fight, but I was counseled not to go into the meeting as a fighter. We didn't want the school department to feel defensive. So I approached it as if I was an educator teaching the team all about Rachel and showing them what would be best for her. I included Early Intervention (PT. OT. Speech and vision therapists), Rachels family advocate, father and mother, school speacial needs department coordinator, princapal of school and school nurse.

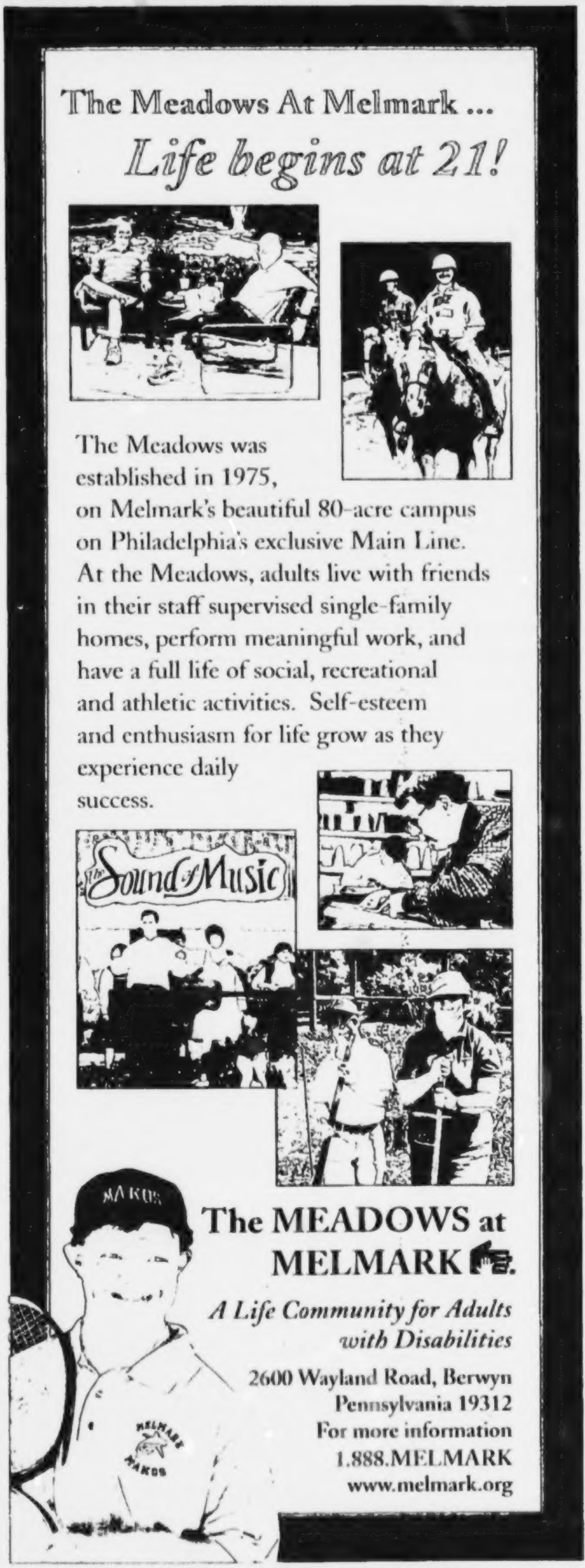
I then submitted a list of concerns such as having a nurse available at all times, a one-on-one aide, a private area for diaper changes, log book to inform the parent of activities and therapy, transportation with a nurse on the bus, bottle feeding on demand, heat/cold concerns, group therapy, an integrated classroom, inclusion in all activities, proper seating and an accessible playground.

To my surprise, they took every concern seriously and worked through each issue one by one. They decided that since Rachel was prone to overheating, they would place her in a school with air conditioning. The only school that could accommodate her didn't have a classroom of three-year-olds, so she was placed in a "typical" Pre-K classroom of four-year-olds. Even though the other children stayed until 2 P.M., Rachel would go home at 11:00. As for the nurse being available, they decided that Rachel's one-on-one aide would be a licensed nurse. The school they chose also had its own physical/occupational therapy room that was filled with equipment.

I was so relieved. I loved this new school. I loved the thought of Rachel being in a classroom of healthy, typically developing four-year-olds. I knew she would do well, although I could sense the fear during the first meeting with the teacher and principal of the school. Of course they were nervous because they didn't know what to expect. The preschool teacher asked me, "What do you expect my role should be?" I simply said, "To include Rachel in everything you do with the other children. Her aide will be there to assist Rachel, but if you pass out paint brushes for a project, please give one to Rachel." She smiled and seemed relieved.

We agreed to have the nurse meet Rachel at our house on Monday and Tuesday prior to beginning school so that she could learn Rachel's cues. Then Rachel would start school on Wednesday of the same week. Well, no one showed up on Monday or Tuesday. On Wednesday I woke up, dressed Rachel, and brought her to school myself. I was determined to have her start school, even if the nurse never showed up. I was Rachel's aide for the day, and it actually worked out well. I was able to slowly wean Rachel into the school environment. I was able to answer the teacher's and

continued on page 60


The Meadows At Melmark ...

Life begins at 21!

The Meadows was established in 1975, on Melmark's beautiful 80-acre campus on Philadelphia's exclusive Main Line. At the Meadows, adults live with friends in their staff supervised single-family homes, perform meaningful work, and have a full life of social, recreational and athletic activities. Self-esteem and enthusiasm for life grow as they experience daily success.

The MEADOWS at MELMARK

A Life Community for Adults with Disabilities

2600 Wayland Road, Berwyn
Pennsylvania 19312
For more information
1.888.MELMARK
www.melmark.org

Circle #38 or visit www.eparent.com/adinfo

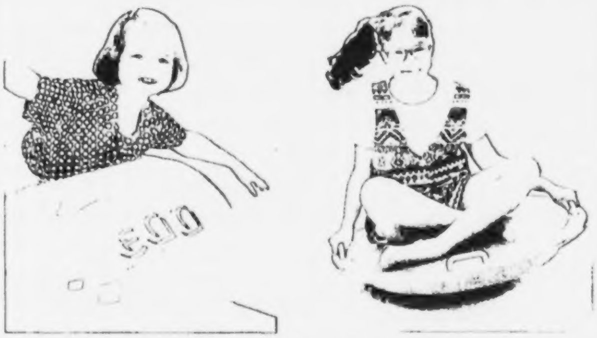
Special Care for Special People

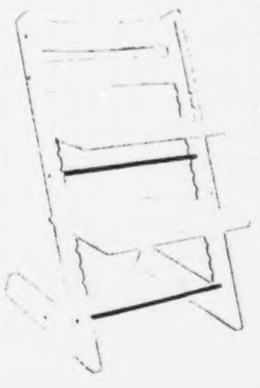
Progressive education, home environment for the mentally challenged child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on an 800-acre bluegrass estate. Est. 1893.

Please write or call for brochure, or visit our web site.

STEWART HOME SCHOOL
4200 Lawrenceburg Road, Dept. B Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician
Phone 502-227-4821
www.stewarthome.com

Circle #46 or visit www.eparent.com/adinfo





We Like Making Kids Happy ...

Send For Free Catalog

equipment shop
P.O. Box 33
Bedford, MA 01730
(800) 525-7681
Fax (781) 275-4094
E-mail: info@equipmentshop.com
Website: www.equipmentshop.com

Circle #27 or visit www.eparent.com/adinfo

continued from page 59

the children's questions and most importantly, I was able to see what a typical day would be for her.

The following Monday the nurse came. On Tuesday she handed in her resignation. Apparently the agency that hired her told her that it was a full time job with benefits. Actually it was three hours a day with no benefits.

When the new nurse arrived, I once again had to go to school with Rachel and teach the new nurse Rachel's cues. She has been with us ever since and Rachel likes her. Hopefully she won't quit.

Rachel's typical day begins with the mini school bus arriving to take her away. I can't help but to smile with pride every day as they whisk her off to school. When she arrives in the classroom, the children stop their activity and run over to say "good morning" and to help Rachel take her coat off. At circle time the children fight over who gets to sit next to Rachel. When the class starts to sing songs, Rachel lights up and tries to sing too. The children get so excited to see Rachel try and they all want to help Rachel move her hands to gesture the song lyrics. During activity time, children request Rachel to join their activity. They are so imaginative to include Rachel in their activity. Rachel spends the entire time laughing and smiling.

Since she started school, she has vocalized so much more and seems so be so active. She just seems so happy. She loves school. If you ask her, "What did you do today at school?" She will open her mouth and move her arms and open and close her fingers. This tells me that she sang songs and played with play dough.

I can't help but think that if I had just accepted the original suggestion of sending Rachel to a special needs classroom at that other school....well, we would never see her be so animated and happy. The EI case manager is in disbelief that the public school system has accommodated us with everything that we requested. The school department told me that they felt that since we were so passionate on not giving up on Rachel, it was their duty to do the same. They also stated that it was unfortunate that more parents don't show as much concern for educating children with severe disabilities.

I just think that maybe those parents didn't know that they could request any other options other than what was offered. When you are fighting for your child's life, it is also hard to challenge organizations that constantly say "no" to requests. It takes perseverance, dedication, and the belief that what you are doing is truly best for your child. EP

Sherri and Ken Epstein live in Worcester, MA with their daughters, Jessica and Rachel. To make a donation to help fund Gene Therapy for Rachel, please send your contribution to Rachel,s Hope, c/o Flagship Bank, 75 Gold Star Blvd, Worcester,MA 01605. For more information on Canavan Disease, please visit www.canavan.org or www.canavanresearch.org.

1383

organizational spotlight

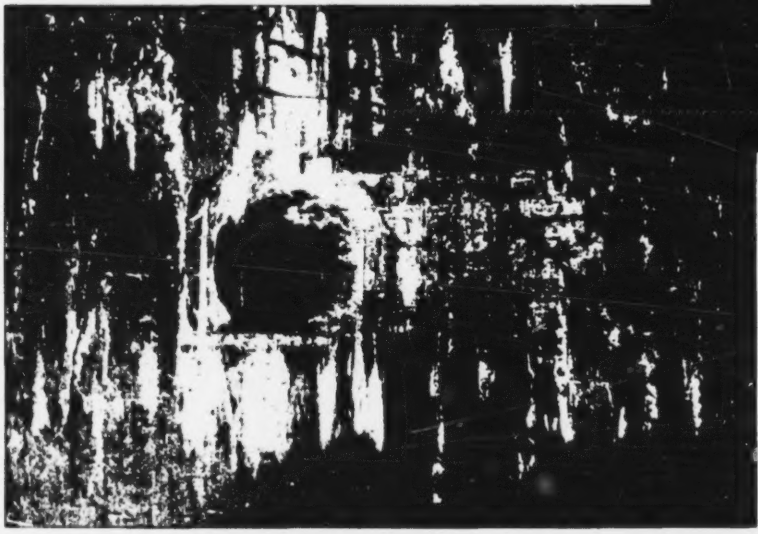
United Brachial Plexus Network, Inc.

When Kim West gave birth to her 10 pound, one ounce baby girl in 1998, she was stunned to see that her daughter had no movement in her right arm. Attending doctors told Kim her child had a brachial plexus injury commonly known as "Erb's Palsy."

The brachial plexus is a network of nerves which conducts signals from the spine to the arm and hand. These signals cause the arm and hand muscles to move. (Brachial means arm, and plexus refers to a network of nerves.) Injury to nerves of the brachial plexus can result in full to partial paralysis of one or both arms.

Stretching, tearing, or other trauma can cause injury to the nerves of the brachial plexus. Brachial plexus injuries most often occur during the birthing process (obstetrical brachial plexus injury) as a result of excessive traction or force being applied to the infant's head during delivery.

Possible symptoms of a brachial plexus injury include: a limp or paralyzed arm; lack of muscle control in the arm or hand. Other terms commonly used to describe brachial plexus injuries include: Erb's Palsy (upper trunk injury); Klumpke's Palsy (lower trunk injury); Brachial Plexus Palsy; Erb-Duchenne Palsy; Horner's Syndrome (when facial nerves are also affected); and "Burners" or "Stingers" (usually associated with sports-related brachial plexus injuries).



Connie Cannon, mother of Kierston Cannon, top left, dedicates her abstract artwork to children with brachial plexus injuries, reflecting the bonding between mothers and babies.

continued on page 62

continued from page 61

Approximately two to three of every 1,000 newborns are affected by brachial plexus birth injuries. More children suffer from brachial plexus injuries sustained at birth than Down's Syndrome or Muscular Dystrophy - yet information on this disability is not so readily obtained. Other frequent causes of brachial plexus injuries include: automobile, motorcycle or boating accidents; sports injuries; animal bites; and gunshot or puncture wounds.

West was stunned because she had been an avid reader of pregnancy and infant books during her pregnancy and had never heard of obstetrical brachial plexus injuries. Immediately, West sought the advice of a neurologist at a local children's hospital on the advice of her pediatrician, although the pediatrician felt there was nothing to be done. The neurologist also recommended a "wait and see" approach, as many obstetrical injuries do make improvements without intervention.

However, West still didn't feel comfortable with the diagnosis and went online to search out more information about brachial plexus injuries. Her search turned up the United Brachial Plexus Network, Inc. (UBPN) web site (www.ubpn.org), which included extensive descriptions of the injury, treatment options, physical and occupational therapy protocols and a message board.

The United Brachial Plexus Network (UBPN) is a registered nonprofit 501(c)3 organization devoted to providing information, support and leadership for families and those concerned with brachial plexus injuries worldwide. West discovered an avid support group online, with parents throughout the world sharing information about the injury.

"I was so relieved to have a place to go where other parents were dealing with the same frustrations I was," said West. "I just couldn't believe that my daughter had zero movement in her arm and there was absolutely nothing I could do about it."

Through the UBPN website she found the name of one of the few hospitals in the nation that specialize in obstetrical brachial plexus injuries.

Kierston Cannon, who had the surgery, rejuvenates her muscles at physical therapy.

After contacting the clinic, she found that it is essential that treatment be obtained as soon as possible from medical professionals who specialize in treating brachial plexus injuries. Early treatment for brachial plexus injuries most likely will include occupational and/or physical therapy to help maximize use of the affected arm while preventing contractures (tightening of the muscles and joints).

While each brachial plexus injury is unique, some individuals may benefit form surgery. Highly specialized and experienced surgeons utilize a variety of operative approaches in attempting to maximize an individual's function. Infants with brachial plexus birth injuries who show little or no improvement by the age of four to six months are often candidates for immediate surgery. Older children and adults may benefit from different surgical techniques as well.

UBPN, Inc. recently introduced an online medical resource. The goal of this project is to provide a comprehensive resource listing to aid families and individuals in their search for specialized brachial plexus care.

A sample of other UBPN organized programs include:

- The Outreach Program which includes the publication of a quarterly in-depth magazine with a circulation of 4,500.
- The Wings Program of UBPN which assists families or individuals in need obtain free or reduced medically-related travel.
- The Awareness Program which is dedicated to increasing awareness of brachial plexus injuries among the public at large and to reach new families and individuals affected by brachial plexus injuries and families with newborns.
- The InterACTION Program which is responsible for bringing the

members of the brachial plexus community together for positive interaction and sharing of information and support. The InterACTION program facilitates Camp UBPN, which is held every other year. The next camp is planned for September, 2003 in Silver Bay, NY.

After finding the UBPN web site, West contacted the group to see how she could help reach other parents trying to find more information about brachial plexus injuries. Since her initial contact, she has become involved with Awareness activities and is currently serving as secretary for the UBPN organization.

West's daughter is now four and has had two surgeries to her arm, including nerve grafts to her brachial plexus and muscle releases to increase function. Her daughter has weekly physical and occupational therapy visits, along with daily range of motion and "play" therapy at home.

"Although our improvements have come slow, it is amazing to see my daughter clap with both hands when she had no movement at seven months of age," West said. "I give total credit to the United Brachial Plexus Network and the resources they have available online. Without them, I would have never found brachial plexus experts to help me navigate through the issues of this injury."

It is important to note that even with ongoing therapy treatment and surgical intervention, complete recovery from a brachial plexus injury may not occur. Maximizing functional use of the injured arm in generally the overall goal of affected individuals, families and medical professionals. UBPN is here to help families reach their goal. **EP**

For additional information, contact:

The United Brachial Plexus Network
Nancy Birk, President
1610 Kent St.
Kent, OH 44240
Toll Free Phone Number:
866-877-7004
Fax Number:
866-877-7004
Email Addresses: info@ubpn.org

Camphill Special School
Children's Village
A not-for-profit residential school community where children with developmental disabilities are truly celebrated.

Is your child receiving a caring and compassionate education?

Since 1960, the families at Camphill Special School have invited children with special needs into their homes and into their hearts; living together as extended families they share the daily rituals of meals and chores, as well as the challenges of school and therapy.

Each House Parent has received specialized training and is prepared to nurture your child's capabilities and guide them toward a brighter future.

- **Pennsylvania Approved Private School**
- **Waldorf Curriculum (Member of AWSNA)**
- **Both Day & Residential Programs Available**

discover how rich life can be

1784 Fairview Road • Glenmoore, PA 19343 • 610.469.9236
www.BeaverRun.org

REACHING UPWARD

AT THE EVERGREEN CENTER, we believe in learning as a means to personal independence. Combining school and community residence programs, The Evergreen Center creates an individual education program that helps each student become a part of the community.

Call or write for more information, or visit our website www.evergreenctr.org

EVERGREEN CENTER
345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631
Serving students with developmental, medical and behavioral needs since 1981.

Circle #21 or visit www.eparent.com/adinfo

Circle #28 or visit www.eparent.com/adinfo

Health Institution of the Month

THE VALLEY HOSPITAL

For more than 50 years, since its doors opened in August 1951, The Valley Hospital has been at the forefront of providing quality and state-of-the-art healthcare. This includes providing innovative, high-caliber, specialized services to children with special needs and their families.

The Valley Hospital
Valley Health System
Respected Medicine, Respectful Care

ABOUT THE VALLEY HOSPITAL

The Valley Hospital is a fully accredited, acute care, not-for-profit community hospital serving more than 300,000 people in Bergen County, New Jersey and adjoining communities. Its current licensed capacity is 451 beds. Audrey Meyers serves as hospital president and chief executive officer. In 2001, 44,000 individuals were admitted to Valley and 52,600 people were treated in our Emergency Department, making Valley the second busiest hospital in the state of New Jersey. Also in 2001, Valley provided charity care services amounting to $5,894,451.

The hospital is known for its state of New Jersey-designated Neonatal Intensive Care Unit directed by three full-time neonatologists and its Maternal Fetal Medicine Program, overseen by physicians affiliated with New York University School of Medicine. Valley is also the leader in the field of cardiology services.

Recent innovations to the hospital include the opening of The Center for In Vitro Fertilization and Reproductive Endocrinology, in affiliation with New York University School of Medicine. Also, the opening of The Center for Childbirth, offering comprehensive obstetrical, prenatal and neonatal care; the establishment of a state-of-the-art Critical Care Service and a newly renovated Pediatric Unit.

LEADING THE WAY IN SCREENING

Every year, more than 3,000 babies are born at Valley's Center for Childbirth and each is screened for more than 50 metabolic disorders. Rather than wait for a state mandate (New Jersey currently requires that hospitals screen for only 14 disorders), Valley has adopted universal newborn screening and is the first hospital in northern New Jersey to do so. Its universal screening program is conducted with Neo Gen Screening, in a private laboratory.

Newborn screening is performed in the first days of life before the baby leaves the hospital. It offers a simple, inexpensive way of determining whether a baby has a metabolic disorder that if left untreated, could lead to permanent brain damage, even death. Metabolic disorders, which affect about one in 1,000 babies born in the US each year, are inherited genetic disorders that obstruct the body's ability to break down fats, sugars or proteins in food. Most babies born with these disorders look and act perfectly healthy at first. Without newborn screening, the problem is not discovered until the child develops symptoms, which is often too late to prevent permanent damage.

"Metabolic disorders are not common, but when they do occur they are usually serious and may be fatal," says Frank P. Manginello, M.D. and Director of Neonatology at Valley and an active proponent of universal screening. He is also the medical director of Valley's Center for Child Development, a diagnostic and therapeutic facility for children with developmental problems.

"Our screening program allows us to identify these disorders soon after birth and often start treatment before babies suffer brain damage or other permanent harm." Dr. Manginello has lectured on this topic at two national meetings and was the moderator of "Children at Risk-The State of Newborn Screening" presented by EP and the EP Foundation for Education, Inc.

Valley is also a leader in providing universal hearing screening for newborns. "Recognizing the importance of early detection, The Valley Hospital implemented universal newborn hearing screen-

Audrey Meyers, President and CFO, Valley Hospital

ings long before it was state mandated," says Valley Audiologist Elizabeth Lanza, M.S., CCC-A. Studies show that early diagnosis and intervention can minimize developmental delays that arise from hearing impairment and that infants who receive intervention before six months of age maintain language development commensurate with their cognitive abilities. "Therefore," says Ms. Lanza, "early screening, follow-up and treatment are critical."

SPECIAL CARE RIGHT FROM THE START

More than 250 newborns are admitted to Valley's 15-bed Neonatal Care Unit (NICU) each year. Babies in the NICU are usually the tiniest of newborns, often born prematurely with low birth weight. About half of the admissions are unexpected.

The NICU's three board-certified neonatologists are backed by a support staff of respiratory therapists, physical therapists, pediatric pharmacists, social workers and nurses. 99.9 percent of the babies have successful outcomes and the complication rate is very low, even for the smallest babies.

Associate Director of Neonatology, Carly Pané, M.D. and Dr. Manginello, author of the book, *Your Premature Baby*, have both appeared in New York magazine's prestigious annual Best Doctors list. The NICU medical staff also includes Neonatologist Beth Benjamin, M.D.

The state-of-the-art NICU was designed with every precaution for seriously ill infants and for increased monitoring capabilities, as well as visibility from the nurses' station. Walls were treated with insulation to reduce noise levels. There is softer lighting that studies show has a positive impact on NICU babies.

Dr. Pané points out that the NICU team is committed to providing individualized, family-friendly care. "We have always believed strongly in getting parents involved from the beginning and giving families as much support as possible," she says. "The average length of stay for NICU babies is two weeks, but some are with us for two months. That's a long time for parents to be separated from a newborn - time in which they may begin to feel a loss of control, instead of being directly involved with the baby's progress."

Dr. Manginello adds that additional spacing surrounding each bassinet affords privacy for visiting parents. He is a strong believer in the benefits of "kangaroo care" for sick infants, noting that studies have shown that babies thrive better with skin-to-skin contact. Privacy in the NICU allows a mother to sit with the newborn, creating a 'pouch' on her chest in which the tiny baby can snuggle.

"Our unit allows us to provide highly technological but friendly, family-focused care," Dr. Manginello says. "And with staff coordination, there's a continuous liaison between the NICU and the Center for Child Development."

HELPING SPECIAL NEEDS CHILDREN REACH THEIR POTENTIAL

Imagine a youngster who never gets to ride a bicycle because of developmental delays that make it impossible for him or her to operate one. Now imagine the same child helmeted and atop a specially equipped bicycle that, with help from a therapist, can be controlled with hands. Anyone who observes the happy faces of parents and children at the Center for Child Development will recognize this as a rare and wonderful kind of therapy.

Valley's commitment to the continuum of care for children with special needs and their families is most evident at The Center for Child Development, a diagnostic and therapeutic facility for children ages newborn to 16 that was an outgrowth of the NICU. The Center's services include:

- speech, physical and occupational therapies;
- evaluations and treatment for sleep problems;
- audiology services;
- counseling and social services;
- pulmonary care;
- nutrition counseling;
- parent support groups;
- educational assessments;
- high-risk newborn follow-up.

All these services give children and their parents the comprehensive care that is needed to deal with a variety of medical behavioral or developmental concerns.

The Center opened its doors in 1991 after Dr. Maginello recommended that Valley establish a program to assist children with special needs discharged from the NICU. "Initially, we founded the Center to serve as a resource for special-needs or at-risk babies identified in the NICU," Dr. Manginello explains. "The Center has grown to accommodate the needs of children in the community and today NICU patients make up the minority of children who receive services at the Center."

Children can present at any age, from infancy through school age, with developmental, behavioral and learning issues. When parents or professionals have concerns about a child's development, the Center can provide comprehensive neurodevelopmental and psychoeducational evaluations. Lisa Nalven, M.D. and Director of Developmental/Behavioral Pediatrics and school psychologist Lois Hochberg, M.A., Ed.M., collaborate to recommend interventions that support each child's optimum development. **EP**

PHARMACOLOGICAL Treatment Options FOR AUTISM, PART 1

By C.T. Gordon, III, MD

Psychopharmacologic research over the past several decades has given us a safe and effective supply of medications which can be applied to the treatment of autism. Many stem from the treatment of such conditions as attention deficit hyperactivity disorder (ADHD), anxiety disorders, depressive and bipolar disorders and psychotic disorders.

These medications effectively treat a number of symptoms and behaviors frequently present in individuals with autism. These include hyperactivity, impulsivity, attentional difficulties, anxiety, obsessive-compulsive symptomatology, repetitive motor behaviors (for example, tics and stereotypies), depression, mood swings, agitation, aggression, self-injurious behavior and insomnia.

Most of these clinical characteristics are considered "associated behaviors" in autism. Impairments in certain aspects of attention (for example, joint attention) and repetitive, ritualized behaviors are examples of core autistic symptomatology, which can be positively affected by medication.

The ultimate goal of medication in an individual who has autism is to prepare the brain's physiology to take optimal advantage of other aspects of treatment. These efforts include behavioral, educational and other experiential learning that can directly address core autistic cognitive impairments such as receptive, expressive, and pragmatic language abilities, social deficits and self-directed, repetitive behavior. In other words, pharmacologic intervention should typically be viewed as only one part of a multi-modal treatment plan for an individual with autism.

Overview of Medications

In this two-part series, we will focus on four major groups of medications: neuroleptics, anti-depressant/anti-anxiety agents, stimulants and anticonvulsants. It will become readily apparent that many of these medications affect more than one symptom or behavior. That is, they are relatively nonspecific in terms of their benefits. For each of these commonly prescribed groups of medications, general indications and side effects will be discussed.

As the medical community gains a better understanding of the genetics and biochemistry of autism, it will be possible to develop pharmacologic therapies which directly address underlying abnormalities; ie, more specific treatments.

However, the potential benefits of these nonspecific medications should not be underestimated. In some individuals they can result in a significant increase in the rate of learning or reduce aggressive behavior for an individual with autism so that institutionalization can be avoided.

It must be recognized that different people may respond to the same medication quite differently and an individual's response at different stages of brain development may vary depending upon age, associated medical conditions and other factors. For example, a medication which produces a behavioral side effect preventing its use for a child at age seven may not produce this side effect and be quite useful at age ten.

The brain is continually developing, especially during the first 21 years of life, and this needs to be taken into account. Because of individual differences in brain chemistry as well as differences in the rate of metabolism (breakdown) of medications, markedly different doses may be required for different individuals.

No Guessing

Even though the situation is quite complex, the prescription of medication for autism is not purely a "shot in the dark." Patients are not guinea pigs, and a physician should not simply prescribe whatever first comes to mind as an experiment.

Optimizing the benefits of the available medications requires the physician to bring to bear both art and science. Accurate conceptualization of symptoms and behaviors into groups of treatment-relevant target symptoms is necessary for medications to be effective.

There have been multiple scientifically sound, double-blind, controlled studies of all these medications. Most have been done on adults with other conditions; however, there is a sound base of information on psychopharmacologic agents from studies in children and a growing body of scientific data on medications in children and adolescents with autism. The prescribing physician needs to be aware of these studies and experienced in the pharmacologic treatment of patients with severe neurodevelopmental disorders, including autism.

Optimizing the benefits of the available medications requires the physician to bring to bear both art and science. Accurate conceptualization of symptoms and behaviors into groups of treatment-relevant target symptoms is necessary for medications to be effective. These interpretations and judgments are based on history from parents, teachers and other therapists, as well as direct observation of the individual with autism.

Clear target symptoms need to be established, information about transient and long-lasting possible side effects should be outlined, dosing should start low and escalate carefully, and a trial needs to be conducted for an adequate length of time.

Furthermore, medications need to be prescribed systematically. There is no room for "magic concoctions." Medications need to be prescribed one at a time so that effectiveness and side effects can be accurately determined. There are certainly times when a patient benefits from a combination of medications, but excessive polypharmacy should be avoided.

Neuroleptics

Neuroleptics, also called anti-psychotic medications, have been the most widely studied class of psychopharmacologic agents in autism over the past 35 years. The drugs were originally developed for the treatment of schizophrenia, a psychotic illness with prominent delusions, hallucinations and disorganized, illogical thinking.

Until the mid 1970s, autism was hypothesized to be a very early onset form of schizophrenia; this formed

continued on page 68

continued from page 67

part of the rationale for using these agents in autism. Neuroleptics are effective in treating severe anxiety, agitation and aggression in several non-schizophrenic populations and there was hope they would provide similar benefits to individuals with autism. In addition, neuroleptics are strong blockers of the neurotransmitter dopamine. (During the 1960s and early 1970s, a "dopamine theory" was used to explain autism, suggesting that excessive dopamine was responsible for much autistic symptomatology.)

Since the 1960s, there have been multiple controlled studies of neuroleptics in children and adolescents with autism, with the majority involving drugs like haloperidol (Haldol) and lesser numbers with thioridazine (Mellaril) and trifluoperizine (Stelazine). These neuroleptic agents were found to decrease hyperactivity, stereotypic behavior (self-stimulatory, simple and complex movements), withdrawal, aggression and temper outbursts, and facilitate learning in children with autism.

Since the 1960s, there have been multiple controlled studies of neuroleptics in children and adolescents with autism, with the majority involving drugs like haloperidol (Haldol) and lesser numbers with thioridazine (Mellaril) and trifluoperizine (Stelazine).

The problem with these neuroleptics is their side-effect profile, which includes sedation as well as acute and chronic neurologic side effects. Acute neurologic effects (extrapyramidal effects or those involving descending nerve tracts other than the pyramidal tracts) include tremors, slowing down of movements and stiffening of the muscles (a Parkinson-like syndrome). More chronic neurologic side effects include withdrawal or tardive dyskinesias. Dyskinesia is a syndrome that causes potentially irreversible, involuntary dyskinetic movements, which may develop in patients who have been treated with anti-psychotic medications. Withdrawal dyskinesia involves abnormal movements that occur for several weeks to months when the dosage of the neuroleptic is lowered too rapidly. Tardive dyskinesia is a similar involuntary movement disorder which may occur, usually, after years of neuroleptic treatment. However, it can sometimes occur with shorter courses of treatment. In some cases, even if the neuroleptic is discontinued, the tardive dyskinesia can continue and become permanent.

Haldol and the Newer Narcoleptics

Despite their adverse effects, Haldol and similar neuroleptics remained the major medications used in autism until the 1990s. Over the past eight years or so, a new generation of neuroleptics has been introduced on the market with equal or better effectiveness for schizophrenia and far fewer side effects. This new group of neuroleptics shares some similar chemical effects with the older neuroleptic group, but there are also important differences. In general, the new generation of neuroleptics has less success in blocking dopamine type II brain receptors but more in blocking dopamine type I receptors, and much more blockade of several different types of serotonin receptors. These drugs have been called "atypical neuroleptics" because of their similar clinical effects but differing neurochemical profile. Presently the four that have been approved by the FDA and widely available are

Atypical neuroleptics generally are equal to or better than the old group of neuroleptics in terms of effectiveness and superior in terms of side effects. Usually, in clinical practice, one or more atypical agents are first tried before the older neuroleptics are considered.

risperidone (Risperdal), olanzapine (Zyprexa), clozapine (Clozaril), and quetiapine (Seroquel).

Risperidone

Risperidone is the only one of the four atypical neuroleptics that has been investigated in a controlled study of autism. Researchers found risperidone to effectively treat motor stereotypes, hyperactivity, impulsivity, agitation and aggression in a double-blind placebo controlled study. Recently, the New England Journal of Medicine published a controlled study of risperidone in children with autism that reported the drug was useful in controlling aggression and self-injurious behavior in children with autism and related disorders. This large-scale study was funded by the National Institute of Mental Health (NIMH), which is currently sponsoring several childhood psychopharmacologic studies as part of its research units for pediatric psychopharmacology (RUPPs).

Numerous open-label trials and case studies of risperidone in autism have had similar results. Thus far, the side effects profile of risperidone in individuals with autism has been favorable. Neurologic side effects are shown to be drastically reduced, although acute extrapyramidal symptoms still occur. The potential for tardive dyskinesia is as yet unclear, since risperidone has not been on the market long enough for it to be fully assessed. The most common side effects of risperidone have been increased appetite and, less often, sedation.

Olanzapine

Olanzapine is probably the second most prescribed atypical neuroleptic (after risperidone) for autism, although, to date, there are no published controlled studies involving individuals with autism. In my experience, benefits and side effects are similar to those seen with risperidone overall. However, an individual patient often responds much better to one versus the other, and there is no way to predict which of the two may be more beneficial.

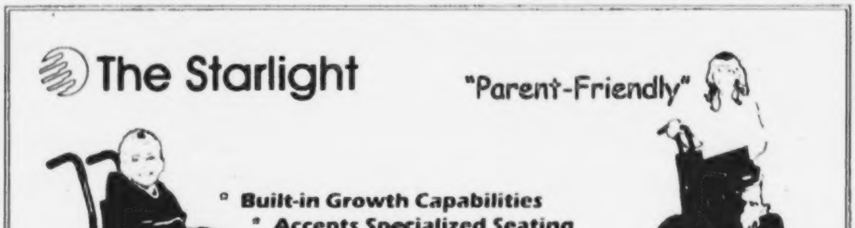
Clozapine

Clozapine is more rarely used because it has a possible life-threatening side effect of lowering the white blood cell count, so that regular blood testing is required as long as the patient continues to take the medication. However, in my experience, clozapine has been an extremely effective medication for severe aggression and agitation in very affected, treatment-resistant adolescents with autism spectrum disorders (ASD). It has worked when nothing else has.

Quetiapine

Quetiapine is the atypical neuroleptic that has most recently appeared on the US market. There is little published data regarding quetiapine for autism, but my clinical experience is that it may be a useful alternative, especially when patients have prohibitive side effects with the other atypical neuroleptics. Thus, even though its role in autism

continued on page 70



The Starlight

"Parent-Friendly"

- Built-in Growth Capabilities
- Accepts Specialized Seating
- Lightweight - 55 lbs !
- 10 Second Folding
- Easily Transportable
- Excellent Travel Chair
- Adult Chair Available

Pediatric Power-chair

NEW

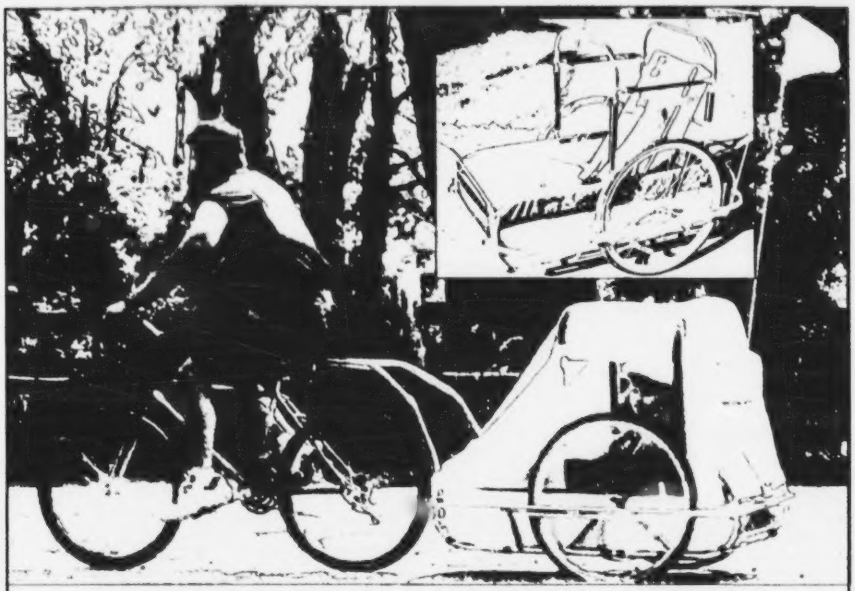
- Built-in Programmability
- Digital Electronics
- Compact Design
- Illuminated LCD Display
- Remote Joystick Option
- Optional "Lock-out" Mode

Global Power Systems, Inc.
www.globalpowersystems.com
(800) 554-8044

Personalized Power Controller

Made In U.S.A.

Circle #31 or visit www.eparent.com/adinfo



Enjoy the out-of-doors together with a

CycleTote® Bicycle Trailer
Running Stroller

1-800-747-2407 www.cycletote.com

Satisfaction Guarantee/Lifetime Warranty

visit www.eparent.com/adinfo

Get More Out of Vestibular Stimulation with The Motion Table

The Motion Table enables therapists to deliver the value of vestibular motion to their patients without the need for constant hands-on intervention.

Most stimulation equipment available today reduces the therapeutic effect of *horizontal motion* by incorporating rounding, swinging and tilting motions. **The Motion Table**, through its smooth, "vibra glide" movement provides a steady, uniform stimulation that can help "level out" extremes in patients' behavior.

And, since **The Motion Table** is motorized, patients can be stimulated for longer periods than is possible with manual equipment.

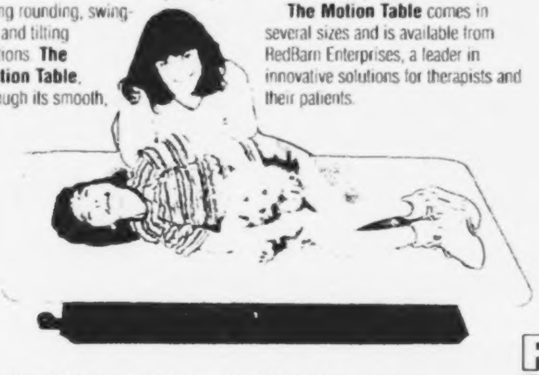
The Motion Table comes in several sizes and is available from RedBarn Enterprises, a leader in innovative solutions for therapists and their patients.

The Motion Table reduces...

- *Hypersensitivity*
- *Self-abuse*
- *Abnormal Muscle Tone*
- *Constipation*
- *Pulmonary Congestion*

The Motion Table increases...

- *Concentration*
- *Attentiveness*
- *Calmness*
- *Body Awareness*
- *Postural Control and Balance*



RedBarn
ENTERPRISES

Try The Motion Table AT NO RISK for 30 days.
Try it for a month. If you're not completely satisfied, just send it back for a complete refund.

For a copy of a just-released Technical Evaluation of The Motion Table or additional product information, call us at 1-800-577-1317, or visit us on the Worldwide Web at www.redbarn-enter.com.

For more information on **RedBarn**, or to place an order, call **1-800-577-1317**, email us at: info@red-enter.com, or visit our web site at **www.redbarn-enter.com**

Circle #42 or visit www.eparent.com/adinfo

continued from page 69

is yet to be established, it is showing some initial promise.

To summarize, neuroleptics are very useful for a group of children with autism who have prominent hyperactivity, impulsivity, agitation, temper outbursts or aggression towards self or others. Often, once these behaviors are reduced, these individuals can make better use of behavioral and educational interventions. Atypical neuroleptics generally are equal to or better than the old group of neuroleptics in terms of effectiveness and superior in terms of side effects. Usually, in clinical practice, one or more atypical agents are first tried before the older neuroleptics are considered. However, to date there has not been a study directly comparing atypical to typical neuroleptics in autism.

Next month: Using Anti-Depressants and Anti-Anxiety Agents, Stimulants & Other ADHD Medications and Anticonvulsants in the treatment of autism spectrum disorders. EP

Editor's Note: Readers should remember, as Dr. Gordon state's in this article, that pharmacological treatments are not cures for autism spectrum disorders, but assist in helping to manage some symptoms of autism and related disorders that are similar to symptoms associated with other neurological disorders. To determine whether your child may benefit from pharmacological interventions to treat autism, talk your child's pediatrician and/or child psychiatrist.

C.T. Gordon, III, MD, is a child psychiatrist in private practice in Bethesda, MD and a trustee of the National Alliance for Autism Research (NAAR). He is also the father of a child with autism and currently serves on NAAR's Medical Affairs Committee.

For Further Reading...

by Megan Henninger

Looking for more information on the education opportunities that exist for your child? These titles offer a glimpse of those available to help you! Access these and other titles by contacting the EP Library online (http://www.eplibrary.com), by fax (201-947-9376) or by calling (800) 535-1910.

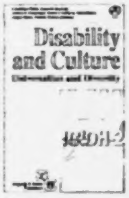
For Adults...

We're the People, Too: Tales from America's Largest Minority
BY WALT DUDLEY ITRICH
☆☆☆☆
EP Library Code: CP0266GN
EP Library Price: $16.95

Since 1994 Itrich has been in contact with the people whose stories are told in this book. This book takes "Chicken Soup for the Soul," and combines it with facts and other information to not only inspire those with a disability, but also help them learn about the problems they may encounter. From spinal chord injuries to ADA to AIDS, there's a story in this book that can educate and affirm everyone.

My Journey with Jake
BY MIRIAM EDELSON
☆☆☆☆
EP Library Code: BTL7350GN
EP Library Price: $ 14.95

Miriam Edelson's story has spread across the continent because of the love and devotion she displays, and this book is no different. The book follows her son through birth, diagnosis and each illness and decision that accompanied his every day. Through the story of her son's life readers are reminded what pediatric health care should be from one of their best advocates, the parent.



Disability and Culture: Universalism and Diversity
BY USTUN, CHATTERJI, BICKENBACH ET AL.
☆☆☆
EP Library Code: HHP239XGN
EP Library Price: $44.50

This professional resource presents the findings of the ICIDH-2 cross-cultural Applicability Research study conducted between the World Health Organization, the US National Institutes of Health and multiple centers worldwide. The results presented discuss cultural factors that contribute to disabilities, access to healthcare and social stigmas that surround those with disabilities in countries that include but are not limited to Canada, India, Cambodia, Luxembourg, Japan, Nigeria, Spain and many others.

Asperger Syndrome Employment Workbook
BY ROGER N. MEYER
☆☆☆
EP Library Code: TF7960AS
EP Library Price: $29.95

This resource can be used by any individual with a disability, not just those with Asperger syndrome. Sections I and II provide detailed yet simple instructions and examples that will help the reader complete Section III. This final section consists of pages of questions that can help a person expand their self-knowledge and learn more about what job would suit them through carefully planned exercises and an intense look at their previous work experience.

For Kids...

Paul and Sebastian
BY RENE ESCUDIE & ULISES WENSELL
☆☆☆
EP Library Code: KP1499YLP
EP Library Price: $6.95

Paul lives in a green trailer with blue curtains and Sebastian lives in a blue apartment with green curtains. Though their mothers think they're too different to play together, the boys learn otherwise, and eventually teach their mothers this same lesson. Differences become negligible in this story of two boys, teaching children that having different lifestyles shouldn't prevent people from being friends.

The Giantess
BY EVELINE HASLER & RENATE SEELIG
☆☆☆
EP Library Code: KP1766YP
EP Library Price: $12.95

Emmeline has always lived in seclusion at the end of the forest because she's taller than the village folk. When a neighbor convinces her to attend a carnival where she can pass her secret off as a costume, she learns that there's more to being a good person than height. The children of the village offer her acceptance and friendship while teaching her that she can help them do wonderful things simply because she's different.

EP'S EXCEPTIONAL EVALUATIONS: ☆☆☆☆ : EXCEPTIONAL, ☆☆☆ : INSIGHTFUL, ☆☆ : BENEFICIAL, ☆ : HELPFUL

This Holiday Season's Best Buy: OPTIMISM

Raising a child with challenging behaviors is stressful for parents. Research suggests that an optimistic outlook on life buffers this stress.

How does one acquire "optimism?" When I was a little girl, my grandfather used to say: "Half the things you worry about never happen." My response always was, "But what about the other half?" Was he the optimist and I the pessimist? It's not that simple. He viewed life without worry to be the same as optimism. I viewed realistic appraisal of things that can't be helped or changed as calming. At the very least, one can feel "pleasantly surprised" if those things you worry about don't happen!

> **Half the things you worry about never happen!**

Researchers have begun to study the personality trait of Optimism-Pessimism, and, no surprise, optimism is better for you. Optimists have a favorable outlook on life; they believe that good rather than bad things will happen to them. Furthermore, they are more likely than pessimists to face adversity and stress with continued effort. Edward Chang, at the University of Michigan, and his associates have researched optimism and pessimism in adults. Among other things, they found that optimism is associated with, and leads to, securing positive outcomes, whereas pessimism is associated with, and leads to, negative outcomes.

Researchers can conceptualize optimism

Researchers distinguish between two kinds of optimism: optimistic explanatory style and dispositional optimism. People who have an optimistic explanatory style have developed a method of explaining away bad events, perhaps seeing them as only temporary ("She will certainly outgrow this") or very specific to one situation rather than as applicable to their entire lives ("He only throws temper tantrums at home – no where else, so it's not really a problem.") Optimists may believe that failures aren't their own (or their child's) fault, but rather, due to the circumstances ("She never would have done that if the teacher were more sympathetic.")

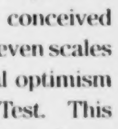
Dispositional optimism represents generalized positive expectancies about future outcomes, broadly conceived ("Everything will turn out just fine.") There are even scales that researchers can use to assess dispositional optimism and pessimism, such as the Life Orientation Test. This measure contains items such as: "In uncertain times, I usually expect the best," or, "If something can go wrong for me, it will."

An optimistic outlook makes a difference?

There is considerable evidence that optimism is beneficial to one's physical and mental health. Studies reveal, for example, that optimists have fewer illnesses and doctor visits, fewer accidents, better physician ratings of their general well being, and longer survival times following a heart attack or disease. Optimists even have longer lives!

Researchers have attempted to identify how optimism actually leads to healthier outcomes. One theory is that a positive attitude produces less stress on one's immune

Dr. Jan Blacher is a Professor in the School of Education at the University of California, Riverside, where she has been a researcher for 20 years. She is currently the principal investigator of the UC Riverside Families Project, a study of families of children with severe disabilities. Over 600 families have been involved in the Families Project research; their participation has contributed to our knowledge about family coping, the cultural context of mental retardation, dual diagnosis and the transition to adulthood. Dr. Blacher has developed **Research Reflections** as a forum for communicating exclusively with parents. The purpose of this column is to provide "news you can use." She is eager to read your reactions to **Research Reflections** and any suggestions you might have. Send e-mail to: jan.blacher@ucr.edu.



system. Another theory focuses on the more rewarding social relationships enjoyed by optimistic people. Still another theory begins with the different thinking (cognitions) of optimistic and pessimistic people. While pessimists focus on negative aspects of a situation, optimists are more likely to see positive as well as negative aspects. Moreover, optimists are more likely than pessimists to interpret negative events in a positive way and to find meaning and growth in stressful experiences.

Aaron Beck and his colleagues have found that chronic engagement in pessimistic thinking can result in ready access to negative schemas, instinctive ways to scan one's world and to select out negative aspects. Negative thinking leads to negative emotions, such as anxiety or depression.

Other constructs, similar to optimism, also show positive relationships to parental well being.

Imagine two parents, one optimistic and one pessimistic, accompanying their child with a disability to a new school on the first day. The pessimist sees his child playing alone, interprets this as rejection by the other children, and comes away remembering that his child has social problems. He's feeling down. The optimist sees her child playing alone also, but she also perceives the neat playground equipment and the welcoming teacher. She comes away remembering all of this, and also interprets her child's solitary play as initial hesitation in a new situation that will be soon overcome. She's feeling happy.

Stress and Optimism

Stress is a fact of life in most families with children, and there is overwhelming research evidence that families who have children with disabilities experience more than their fair share. Heightened parenting stress has been documented across ages, stages, and different specific disabilities and genetic syndromes. However, that's not the whole story. To counter-balance this more pessimistic view of family impact, recent studies also have demonstrated the positive impact of a child with disability on the family.

During most of the 20th century any parent who expressed positive views of having a child with a disability might have been viewed as in denial, or as rationalizing a bad situation. However, Ann Turnbull and her colleagues at the University of Kansas Beach Center on Families and Disability, recognized the fallacy in this, and focused their theory and research on the positive benefits from having a family member with a disability (spelled out in the book, Cognitive coping, families, and disability, 1993). They viewed cognitive coping strategies, such as those used by our optimistic mother in the example above, as a positive adaptation to stress. For example, some parents reported that just having a child with disabilities strengthened their own adaptive capacity.

Optimism helps meet parenting challenges

There is some evidence, albeit not entirely consistent, that mothers high in optimism experience less negative impact on their own well-being from their children's challenging behavior. Bruce Baker at UCLA, Malin Broberg Olsson (a Fulbright Student Scholar visiting from the University of Trollhattan-Uddevalla, Sweden) and I have been studying whether the individual personality trait of dispositional optimism can serve as a "buffer" between child behavior problems and parent well being. We are finding that when child behavior problems are low, optimistic and pessimistic parents report similar scores on measures of well-being. Parental well-being worsens as child behavior problems increase, however, and then we see the benefits of an optimistic outlook. When child behavior problems are high, optimistic mothers show the least decrease in well-being, while pessimistic mothers show a much greater worsening of stress, depression, and marital adjustment.

Other constructs, similar to optimism, also show positive relationships to parental well being. Richard P. Hastings and Tony Brown of the University of Southampton, England, examined "self-efficacy" and how it relates to well being in parents of children with autism. In this study, self-efficacy referred to parents' perceptions of their own skills in dealing with children who had behavior problems. As with optimism, self-efficacy moderated depression; when child behavior problems were high, parents who perceived greater effectiveness in dealing with their child's problems reported less depression and anxiety.

Optimism is free

We are reminded of the cartoon of a man holding a placard at a stoplight that reads: "Please help! I'm a pessimist hav-

continued on page 77

Getting information from

EP advertisers is

MUCH FASTER

ONLINE!

It's as easy as a click
of *your* mouse!

Here's all you have to do:

1. Simply log on to our web site, www.eparent.com.
2. Click on the "free information" icon.
3. Request your information (select advertiser name, circle number and product type).

WWW.EPARENT.COM

Free, Easy and
FASTER!

FREE
Information
from Advertisers
CLICK!

For quick, easy access to our advertiser's websites use: www.eparent.com/adinfo

FREE PRODUCT & SERVICE INFORMATION

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS!

This Reply Card enables you to receive FREE information about products and services seen in EXCEPTIONAL PARENT.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.

Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

DIRECTORY OF ADVERTISERS

CIRCLE#	ADVERTISER	PAGE#
19	ADAPTIVEMALL.COM	52
17	ANNANDALE VILLAGE	8
20	BODYPOINT DESIGNS, INC.	50
21	CAMPHILL SPECIAL SCHOOL	63
22	COLUMBIA MEDICAL	23
23	CROTCHED MOUNTAIN	55
24	CRYSTAL SPRINGS SCHOOL	89
25	CYBERONICS, INC.	10-12
	CYCLETOTE CORP.	70
26	EDEN FOODS, INC.	5
200	EP LIBRARY	27,86-87
199	EP SUBSCRIPTION PAGES	17-18
27	EQUIPMENT SHOP	60
28	EVERGREEN CENTER	63
29	FORD MOBILITY	C3
30	FREEDOM MOTORS USA	30
	GENERAL MOTORS	C2
31	GLOBAL POWER SYSTEMS INC	69
32	H.D.I.S.	40
33	HARD MANUFACTURING	16
18	HEARTSPRING	41
34	HMS SCHOOL	52
	HOUSE AD	74
35	JOHN HOPKINS UNIVERSITY PRESS	81
36	LAWYERS, INC.	33
37	LITIGATORS, INC.	21
38	MELMARK	59
39	MUELLER LAW OFFICES	79
40	OCEAN HYPERBARIC CENTER	36
41	OTTO BOCK	7
42	RED BARN ENTERPRISES	70
43	ROSS LABORATORIES	15
44	SIGMA TAU	1-2
45	SNUG SEAT INC.	9
46	STEWART HOME SCHOOL	60
47	THE COLE CENTER FOR HEALING INC.	57
48	VAIL PRODUCTS	C4
49	VERIZON	3
50	WOODBURY PRODUCTS	81
51	WORLD CONGRESS	84-85

SUBSCRIPTIONS

EXCEPTIONAL PARENT, P.O. BOX 2078, MARION, OH 43305-2078
(877) 372-7368 New Orders/Customer Service
For international customer service, call 201-489-4111

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in Exceptional Parent does not constitute nor imply endorsement by Exceptional Parent magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Exceptional Parent, 65 East Route 4, River Edge, NJ 07661. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

PHOTOCOPYING: Nothing may be reprinted in whole or in part without written permission from the publisher. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Psy-Ed Corporation for users registered with the Copyright Clearance Center (CCC) Transactional Reporting Service, provided that the base fee of $2 per copy, plus $.75 per page is paid directly to CCC, 222 Rosewood Drive, Danvers, MA 01923. Customer Service: 508-750-8400. For the organizations that have been granted a photo copy license by CCC, a separate system of payment has been arranged. The fee code for users of the Transactional Reporting Service is: 0046 9157/89/$2.00 + .75.

MICROFILM: Microfilms of all issues are available from University Microfilms,
300 North Zeeb Road, Ann Arbor, MI 48106

EP

has the information an "Exceptional Parent" like you needs

EP
Exceptional Parent

Subscribe

on our

website:

www.eparent.com

and save

$5.00

For telephone

orders

call:

877-372-7368

To start your subscription to EP today, fill out the card near the front of this magazine or log on to www.eparent.com

EP MAGAZINE **Free product & service information order card*** **DECEMBER 2002**

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?

☐ Yes ☐ No (if no, please visit our web site at www.eparent.com.)

Name ____________________

Address ____________________

City ____________________ State ______ Zip ______

Phone ____________________ Fax ____________________

E-mail ____________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No

If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist ^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist

^{10}☐ Other (please indicate) ____________________

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No

If Yes, are you a: ^{13}☐ Other (please indicate) ____________________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No

If yes, please explain ____________________

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

***CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: May 31, 2003**

BDEC2

EP MAGAZINE **Free product & service information order card*** **DECEMBER 2002**

FAX this card to 413-637-4343 for quicker response

PLEASE ANSWER THE FOLLOWING QUESTIONS:

A. Are you a subscriber to Exceptional Parent ?

☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ____________________

Address ____________________

City ____________________ State ______ Zip ______

Phone ____________________ Fax ____________________

E-mail ____________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ^{1}☐ Yes ^{2}☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ^{3}☐ Yes ^{4}☐ No

If Yes, are you a: ^{5}☐ Physician ^{6}☐ RN ^{7}☐ Physical Therapist ^{8}☐ Occupational Therapist ^{9}☐ Speech Pathologist; Audiologist

^{10}☐ Other (please indicate) ____________________

D. Are you an EDUCATOR? ^{11}☐ Yes ^{12}☐ No

If Yes, are you a: ^{13}☐ Other (please indicate) ____________________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ^{14}☐ Yes ^{15}☐ No

If yes, please explain ____________________

F. Do you use EP to find a product or service? ^{16}☐ Yes ^{17}☐ No

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50
51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75
76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	121	122	123	124	125
126	127	128	129	130	131	132	133	134	135	136	137	138	139	140	141	142	143	144	145	146	147	148	149	150
151	152	153	154	155	156	157	158	159	160	161	162	163	164	165	166	167	168	169	170	171	172	173	174	175
176	177	178	179	180	181	182	183	184	185	186	187	188	189	190	191	192	193	194	195	196	197	198	199	200

***CIRCLE NUMBERS: To obtain FREE information about those products or services that interest you, please circle the number that appears on the advertisement. Expiration date: May 31, 2003**

BDEC2

1403

To start your subscription to EP today, fill out the card near the front of this magazine or log on to www.eparent.com

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

No Postage
Necessary
if Mailed
in the
United States

BUSINESS REPLY MAIL
FIRST CLASS MAIL PERMIT NO. 650 PITTSFIELD MA

POSTAGE WILL BE PAID BY ADDRESSEE

Exceptional Parent
PO BOX 5446
PITTSFIELD MA 01203-9321

Exceptional Parent

is the magazine for exceptional parents with exceptional children. Each month, EP provides a forum to network with others who are providing a richer life for themselves and for their children.

Exceptional Parent's MISSION IS TO BE THE PREMIER INFORMATION SOURCE FOR PARENTS EDUCATORS AND HEALTHCARE PROFESSIONALS DEDICATED TO CARING FOR CHILDREN AND YOUNG ADULTS WITH SPECIAL NEEDS

Don't miss a single issue:

SUBSCRIBE TODAY AND RECEIVE THE 2003 RESOURCE GUIDE GO ONLINE AND SAVE EVEN MORE

EP
Exceptional Parent

www.eparent.com

continued from page 73

ing a good day." Most interventions, though, would be more likely to target individuals who have a bad day, most of the time. Although it is believed that optimistic or pessimistic thinking crystallizes around age nine and remains stable across one's lifespan, it can, in fact, be changed.

The Penn Optimism Program (at the University of Pennsylvania) selects school-aged children who are at risk for depression. They meet in groups of 8 to 12 children, with a leader, for 12 weekly sessions. The curriculum begins with a focus on recognizing pessimistic thinking and then moves on to teaching more optimistic thinking and behaviors that help counteract pessimism (e.g. relaxation, problem solving). Does it work? In a two-year evaluation, participants had half the rate of moderate to severe levels of depressive symptoms than did comparable children who did not participate. Parents can develop a more optimistic outlook as well. For example, the most successful psychological treatment for depression is cognitive behavior therapy, a major component of which is helping people to identify negative thought patterns and to develop alternative ways to view life events.

Heightened parenting stress has been documented across ages, stages, and different specific disabilities and genetic syndromes.

So be sure to put "optimism" on your Holiday gift list. The price is right. Like other "best things in life," an optimistic outlook is free.

A list of studies on which this particular column is based may be obtained by e-mailing requests to: epedit@aol.com. Special thanks to Bruce L. Baker and Malin Broberg Olsson for contributing their ideas about optimism. **EP**

References

Aspinwall, L. G., & Brunhart, S. M. (2000). What I do know won't hurt me: Optimism, attention to negative information, coping, and health. In J. E. Gillham (Ed.), The science of optimism and hope: Research essays in honor of Martin E.P. Seligman, pp. 163-200. Philadelphia: Templeton Foundation Press.

Baker, B. L., Blacher, J., & Olsson, M.B. (2002, March). When is a child behavior problem a PROBLEM? Optimism as a buffer. Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, San Diego, CA.

Chang, E., & Farrehi, A. (2001). Optimism/pessimism and information-processing styles: can their influeces be distinguished in predicting psychological adjustment? Personality and Individual Differences, 31, 555-562.

Chang, E., & Sanna, L. (2001). Optimism, pessimism, and positive and negative affectivity on middle-aged adults: a test of a cognitive-affective model of psychological adjustment. Psychology and Aging, 16(3), 524-531.

Clarke, D., & Beck, A. (1999). Scientific foundations of cognitive theory and therapy of depression (first ed.). New York: John Wiley & Sons, Inc.

Gil, A. ( ). Patient persistence.

Gillham, J. E., Reivich, K. J., Jaycox, L. H., & Seligman, M. E. P. (1995). Prevention of depressive symptoms in schoolchildren: Two-year follow-up. Psychological Science, 6, 343-351.

Glidden, L. M., & Helff, C. (1995). Adaptive and birth parents rearing children with developmental disabilities: Well-being across time. Paper presented at the 119th Annual Meeting of the American Association on Mental Retardation, San Francisco, CA.

Glidden, L. M., & Johnson, V. E. (1999). Twelve years later: Adjustment in families who adopted children with developmental disabilities, Mental Retardation, 37, 16-24.

Hastings, R.P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. American Journal on Mental Retardation, 107, 222-232.

Olason, D. T., & Roger, D. (2001). Optimism, pessimism anf "fighting spirit": a new apprach to assessing expectancy and adaptation. Personality and Individual Differences, 31, 755-768.

Olsson, M., & Hwang, P. (2002). Sense of coherence in parents of children with eifferent developmental disabilities. Journal of Intellectual Disability Research, 46, 1-12.

Scheier, M. F., & Carver, C. S. (1985). Optimism, coping, and health: Assessment and implications of generalized outcome expectancies. Health Psychology, 4, 219-247.

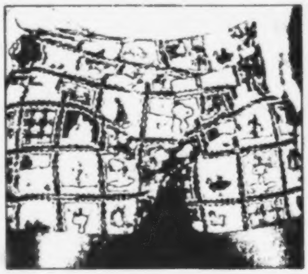
Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A re-evaluation of the Life Orientation Test. Journal of Personality and Social Psychology, 67, 1063-1078.

Turnbull, A. P., Patterson, J. M., Behr, S. K., Murphy, D. L., Marquis, J. G., & Blue-Banning, M. (1993). Cognitive coping, families, & disability. Baltimore, MD: Paul H. Brookes, Publishing Co.

Festive Holiday

PROTECTIVE UNDERGARMENTS

By Lori Ostrover



Children with disabilities need security when wearing undergarments, and they do not want to feel like they have a diaper on. They want to be able to wear what all the other kids are wearing.

Most parents want convenience when a child needs changing. Drymids® Protective Undergarments make products for children with special needs up to the age of 21 and range to fit sizes from 30 to 200+ lbs. The company has recently come out with a new, patented composite fabric that is used on the sides and portions of the front and back of the garments. What makes this fabric so unique is the stretch and recovery. It is also very comfortable and discrete.

The durable fabric is made with Polyester and Lycra. It is more versatile than a knit and has more strength over a non-woven. During the production process the step that makes this fabric greater than others, is the heat that is applied after the fabric goes through the stitch-bonding machine. This heat process brings the stitching closer together and the fabric fills in more. It makes the fabric extra soft, prevents shrinking and reinforces stretch.

Every Protective Undergarment has a built in support system that contains a Pocket-Sling™ manufactured by Tailored Technologies. These hold either a disposable or reusable pad.

Drymids® is dedicated to the special needs market. They will listen to all feedback from their customers and will adjust products based on individual needs the best they can.

They have four main products:

- a basic pull-up • boxer shorts
- double front (frontal flap for the wheelchair bound)
- the "belted" undergarment (one size fits all).

The company is busy making garments with new prints in time for Christmas. There are attractive patterns with Christmas trees, snowmen, stockings and snowflakes. For more pictures and information, visit the web site http://www.drymids.com or call 1-866-DRYMIDS. EP

Easier, Safer Transfers with the NEW LiftVest

Prevent Caregiver Back Injury! Transfer with Comfort and Dignity!

- Stylish vest with webbing harness
- 12 convenient "hand holds"
- Children's sizes: S. M. L. XL
- 30 day Money-Back Guarantee

CALL for a FREE brochure and video
LiftVestUSA:
1-800-300-5671
VISIT OUR WEB SITE:
www.liftvest.com

Fun Baby & Toddler Shoes

First Steps - Shoes that motivate with sound, encouraging movement & exploration
Safety - Hear when your quick moving toddler is on the move. in the house • in the yard • in the mall
Fun - Pre-walkers and walkers LOVE THEM!

Pip Squeakers™

Baby and toddler shoes that squeak softly as each foot touches down.

Visit us at: www.pipsqueakers.com
For more information call (908) 236-4104

ADAPTATIONS
BY ADRIAN
Shirt Savers
Knit and Terry
Protectors — $12

http://www.adaptationsbyadrian.com

Keep your child's brain safe with a 'Cap he'll love to wear.

Children, parents and healthcare professionals have loved ProtectaCap* for over 15 years.

It's hard to tell from this photo that this cute 'Cap is serious protective headgear. Knowing its weight won't help. Josh's 'Cap weighs under 3 ounces. But when you feel a ProtectaCap* you'll see what all the fuss is about.

Abstract technological properties such as cell structure, tensile strength and compression/recovery ratio may not mean much to many of us.

But the benefits they provide do: [illegible]

PROTECTA cap

500 Freedom View Lane
PO Box 85, Valley Forge, PA 19481
Phone: 610-783-7377
Fax: 610-783-7577

plum enterprises, inc.
1-800-321-PLUM

For your convenience and protection, please order your ProtectaCap* on Plum's secure website, www.plument.com.

Photo: © Eclipse Communications Incorporated 2002

Free evaluation.

If you believe someone you love has a life-long disability due to a preventable birth injury—call us now. We are available for consultation to determine if your child's disability was preventable and if you are eligible for compensation. You deserve to get answers to your questions. Call today for a free evaluation.

Mark R. Mueller*
Mueller Law Offices
404 West 7th St., Austin, TX 78701
800-324-5879
www.muellerlaw.com

We specialize in the field of compensation for preventable birth injuries.

The Mueller Law Offices does not, and cannot, guarantee a favorable result in your case. *Member of State Bars of Texas, Louisiana, Wisconsin, Montana; Association of Trial Lawyers of America; Fellowship Member Texas Trial Lawyers Association; Board of Directors-Trial Lawyers for Public Justice; Birth Trauma Litigation Group. Invited seminar speaker on Birth Injury, Trials & Damages presentations to lawyers, medical personnel and risk managers.

© Mark Mueller 2002. Not Certified by the Texas Board of Legal Specialization.

Circle #39 or visit www.eparent.com/adinfo

Risk Genes for ADHD

Researchers from the Center for Neurobehavioral Genetics and other departments at UCLA and the Wellcome Trust Centre for Human Genetics, Oxford, UK have localized a region on chromosome 16 that is likely to contain a risk gene for ADHD.

A report on their research, published in the October, 2002 issue of the American Journal of Human Genetics, suggests that the suspected gene may contribute as much as 30 percent of the underlying genetic cause of ADHD. Other research has suggested that as much as 70 to 80 percent of the cause of the disorder is genetic.

Because this single risk gene may account for some 20 to 25 percent of the overall causes of ADHD, identifying it will help researchers and clinicians to better understand the biology of the condition and probably lead to improved diagnosis, early intervention and treatment.

The human genome has about 35,000 genes, and the research has narrowed the focus to 100 to 150 genes. The gene may also be involved in causing autism. However, Susan Smalley, PhD, principal investigator on the study and co-director of the Center for Behavioral Genetics, cautions that much more research is necessary. While other studies have suggested that the gene causing autism also resides on chromosome 16, it is far too early to determine a distinct risk gene for each disorder or whether certain genes are involved in both disorders. It may be that the risk gene for ADHD and the one for autism just happen to be in close proximity on chromosome 16.

Rise in Autism Attracting Attention

In an attempt to explain the extreme increase in childhood autism in California in the past decade, a study from the M.I.N.D. Institute at the University of California-Davis has discounted changing diagnostic criteria and other statistical incongruities as possible explanations.

As the number of children with autism has increased to what some are calling epidemic levels, parents and researchers have been searching everywhere for some kind of explanation. While everyone seems to have a personal theory on what may trigger autism—genes, childhood vaccinations, environmental factors, birth injuries—no single cause of the condition has been identified.

There are no national statistics on autism, since criteria for diagnoses and systems of reporting incidences vary from state to state. The Centers for Disease Control and Prevention is working in 13 states to look at the apparent increase in autism. It is unclear whether the M.I.N.D. Institute findings apply to the rest of the US.

In California, the number of children with profound autism rose from 2,778 in 1987 to 10,360 in 1998—more than tripling in a decade—and has continued to increase since. According to the California Department of Developmental Services, who reported those statistics in 1999, the number of cases as of July 2002 was 18,460. The 1999 report prompted the California Legislature to commission a further study at UC-Davis. This most recent study ruled out demographics, changes in the way autism is diagnosed and increased migration of children with autism into California as possible explanations for the increase.

In order to examine these possible explanations, researchers conducted a study of 684 children taken from two different age groups: about half of them were ages 17 to 19 years old (born 1983-1985), while the other half were ten years younger (born 1993-1995). Within the overall group, 375 had been diagnosed with full syndrome autism, while 309 had mental retardation and developmental delays (MR/DD) but did not exhibit full syndrome autism.

The study would have revealed any changes in diagnos-

We now have a new monthly in depth look at reports and studies on issues that affect the special needs community. Each issue will feature information on the latest medical and scientific updates that apply to our readers.

tic standards during the ten-year gap, and shed light on whether or not loosening diagnostic criteria were responsible for the increase. The study showed, however, that standards were the same in both age groups. Questions of migration—families moving into the state that had children with autism—were dispelled as well. Fully 87 percent of the older group and 93 percent of the younger children groups studied were born in California. A general increase in population could account for about 10 percent of the overall increase in the rise.

The M.I.N.D. research addressed issues of misdiagnoses, because it had been found that some children diagnosed with MR/DD without full syndrome autism did indeed meet DSM-IV criteria for autism. The study showed that the rate of misdiagnoses was consistent between the two groups.

Half of the parents of children in each age group studied said that they do not know what caused their child's autism. A third of them cited genetics as a cause. Others blamed immunizations, birth injury or environmental factors. Birth injury or environmental factors were cited by roughly the same percentage of parents in each age group. It is interesting to note that while parents of 18 percent of the older cohort reported immunization as a contributing factor, 33 percent of the younger group believed that immunization had played a part.

> Some childhood vaccines have contained mercury-based preservatives that some blame for brain damage in children, but so far no conclusive evidence exists to pinpoint any vaccine as a culprit

Infant immunizations are often blamed for causing autism, especially the measles-mumps-rubella (MMR) vaccine (see EP, February 2002). It is true that, until recently, some childhood vaccines have contained mercury-based preservatives that some blame for brain damage in children, but so far no conclusive evidence exists to pinpoint any vaccine as a culprit.

We know that genetics plays a role in autism, but genetics alone cannot account for such a sudden rise in such a short period. It may be that some other factor can trigger autism in someone whose genetic makeup is already susceptible. In any case, we know that there is no single cause of autism. The rest is still a mystery. EP

SAVE Up To **50%**
On Youth Briefs

We sell and distribute incontinent youth products at
DISCOUNT PRICES!

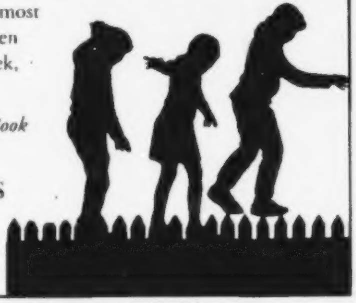
As a service to our customers, we offer **FREE SAMPLES** of disposable youth briefs and pull ups.

Save up to 50%

Call **1 800 777 1111** 24Hrs
WOODBURY PRODUCTS, INC.

Order online at: **www.woodburyproducts.com**

Circle #50 or visit www.eparent.com/ad info



THIRD EDITION

Seizures and Epilepsy in Childhood
A Guide

JOHN M. FREEMAN, M.D.
EILEEN P. G. VINING, M.D.
DIANA J. PILLAS

Winner of the 1991 Epilepsy Foundation of America's National Book Award

"This remarkable book has been empowering parents with vital information for more than ten years, and the new edition promises to do the same. It is committed to making parents active partners in their children's care and will be a vital resource for families everywhere."—Eric R. Hargis, President and CEO, Epilepsy Foundation

"A helpful book . . . Discusses most concerns that parents of children with epilepsy have."—Jay Siwek, M.D., *Washington Post*

A Johns Hopkins Press Health Book
$19.95 paperback

THE JOHNS HOPKINS UNIVERSITY PRESS
1-800-537-5487
www.jhupbooks.com

Circle #35 or visit www.eparent.com/ad info

AAMR

Oral Sensitivity, Dental Health, and Prevention

Lee Barks, RN, MN, ARNP, FAAMR and
Debbie Lord, MA, CCC, SLP/L, FAAMR

AAMR promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities.

Oral Health-An important part of any regimen

To a person with disabilities, oral healthcare may cause pain rather than a sense of well being. Instead of the normal sensation of tooth brushing, these stimuli may feel like burning, cold, searing pain, or some other sensation. The person naturally defends him- or herself. The natural response of many parents is to "be kind" to their child, do what is comfortable and hope for the best. Many say, "We just do the best we can."

The child who is orally hypersensitive may gag at the sight of a toothbrush, vomit, and engage in a battle royal at oral hygiene time. Sometimes compounding the problem, use of some medications like Dilantin can cause overgrowth of the gums, resulting in extra trapping of bacteria and plaque below the gumline. Without treatment, this accelerates and worsens infection and decay.

Good oral healthcare measures are an important part of any regimen.

OUTCOMES

Over time, even if some brushing takes place, some mouth areas may be avoided, and gingivitis, bleeding, then periodontal disease with bone loss, caries (cavities), and sometimes abscesses develop. Tooth mobility (loosening of teeth) develops. At this point, either teeth shed (fall out), or dental acute care takes place.

For the child or young person with oral pain and hypersensitivity, dental acute care can be extremely trying. Sometimes it is difficult to find someone who will prescribe sedation without general anesthesia, and this can further delay care. Medicaid and most health insurance often deny coverage of the expenses involved.

Another outcome for some children and young people is that as teeth are lost oral control of food and fluids decreases. Teeth are needed to provide the structural support to initiate a normal swallow. When they fall out or are pulled, keeping food and fluid moving in the right direction may no longer be possible. The child may begin to experience increased respiratory secretions, coughing, some aspiration, and their voice quality may seem like they are underwater.

Respiratory infections like bronchitis or pneumonia may occur. In some cases, there is a refusal to eat, weight loss, and continual crying.

Oral Motor Therapy and Normalizing Sensation at Home

For children who are orally defensive, this decline is preventable and even reversible, if it has already begun, with consistent, therapeutic oral hygiene. Actually more appropriate stimulation, not less, is needed, and there is hope. Begin with an evaluation from an occupational therapist or a speech pathologist. Following the evaluation, the devel-

This is the third in a monthly series written for EP Magazine by members of the American Association on Mental Retardation (AAMR).

opment of an appropriate program depends on many factors. One of the most important factors is the child's medical status. For the infant or child who is ill or in a coma, direct work is not possible or appropriate.

However, early stimulation and involvement by an appropriate therapist (one who is trained in oral motor therapy) may be beneficial to the family before any direct work actually begins. During illness or hospitalization, pleasant sensory input into the mouth area may be appropriate.

Treatment usually may begin once the child is medically able to maintain a level of brief periods of conscious awareness. Oral motor treatment initiated at the introduction of tube feedings can prevent the oral hypersensitivity and aversive reactions.

Increased experiences with oral input and the people who provide the input greatly influences the child's development of beliefs about the mouth and the entire oral/feeding process. The success of oral motor treatment is primarily measured by the enjoyment of the mouth and increased use for exploration with sensory awareness and discrimination.

Oral motor treatment may include the following:

- Creating a learning environment
- Improving postural control of head, neck and trunk
- Normalizing the response to stimulation
- Improving tone and movements in the lips and cheeks
- Improving tone and movement in the tongue
- Using the tongue and lips to explore the environment

The first step in preventing oral disease is recognizing when your child is orally defensive and engaging an oral motor specialist to provide an evaluation.

If the child is eating orally, but is defensive orally, a gradual introduction to brushing may begin with the use of wet gauze or a washcloth in the mouth. Gradually move to a soft dry toothbrush (small head). Once a dry toothbrush is accepted, a soft wet toothbrush is introduced. It is important that the child is positioned appropriately (as recommended by an occupational therapist). When possible use a nonalcoholic antibacterial mouthwash. This can be used as the cleansing agent rather than toothpaste, particularly with children who are unable to rinse or spit.

ORAL HYGIENE PLANS

The first step in preventing oral disease is recognizing when your child is orally defensive and engaging an oral motor specialist to provide an evaluation. This person should be either a speech therapist or occupational therapist with oral motor experience with children with special needs. Even when there are no mealtime issues, if oral care is difficult, an evaluation is in order, with the expectation that a specific oral hygiene plan that you can execute at home will be written and demonstrated for you. Your child's body position during oral care should be addressed in the plan. You should require that the therapist train you in how to accomplish the plan at home, with follow up and modification if needed, and periodic evaluation of its effectiveness.

Lee Barks, MN, ARNP, FAAMR, is a nurse clinical specialist-consultant in developmental disabilities. She specializes in working with families and health care delivery systems on disabilities health issues. Lee is an active member of AAMR and serves on the Health Promotion and Prevention Committee. She can be reached at LeeBarks@cfl.rr.com.

Debbie Lord, MA, CCC, SLP/L, FAAMR is the Director of Clinical and Healthcare Services at Ken-Crest Services, Plymouth Meeting, PA. She can be reached at dlord@kencrest.org.

Resources

Access To Oral Health Care For Florida's Citizens With Developmental Disabilities: A White Paper. (2002). Florida Developmental Disabilities Council, Inc., Tallahassee, Florida.

Cooper, P.J., & Stein, A. (Eds.). (1992). Feeding Problems and Eating Disorders in Children and Adolescents. Philadelphia: Harwood Academic.

Goldberg, S. (1995). Clinical Neuroanatomy Made Ridiculously Simple. Miami, FL: MedMaster, Inc.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
Hall E1
Hall E2

What People are Saying...

"Merrill Lynch was excited to have the opportunity to participate in the Congress and to bring our team to share their knowledge and experience with the families of special needs children and adults. We look forward to working with the WCD on next year's Congress."
—Nancy Caputo, Assistant Vice President-Global Diversity, Merrill Lynch

"If you thirst for knowledge, this is the place to be. Your one stop for answers."
—Lorilynn Bowie, Marion County Public Schools, Gainsville, FL

"It is like my refueling time for the year when I meet parents and kids that are in the same boat as I. Sometimes we share stories and other times offer support. Best of all you come away feeling refreshed and fired up with a wealth of knowledge that will help in the upcoming year. It is 3 days of fun, fun, fun. If your never tried it, you should. I think you will do as I and return year after year. See ya next September."
—Cari Graham, Babson Park, FL

"This was just great. 3 days with parents who understand." *—Tammy Brown, Lakeland, FL*

"After years of exhibiting at various types of trade shows throughout the United States, we find the WCD show consistently the most rewarding of all. WCD is uniquely able to bring the exhibitor directly face-to-face with the consumer; allowing feedback, fresh ideas and true emotion. What a gift to communicate with these children, to make eye contact, listen, speak, cry, give them a hug, or simply connect with their enormous hearts."
— Kim Gosselin, President, JayJo Books

"Thank you for your dedication to providing the WCD Expo at a reasonable fee which enables families to attend and take part in such an awesome conference! I have attended all three WCD's and plan to return next year. The classes that are offered never fail to enlighten me in at least a couple of subjects, usually in many. The expo hall is also a grand learning experience that I greatly appreciate. It is such a wonderful opportunity for my little girl to be able to actually try adaptive equipment and for me to be able to know (before I begin the ordeal of seeking funding) that a particular item is just right for her. Thank you from both of us for a job well done."
—Kathy Noyes, Davenport, FL

"As a student of occupational therapy, this conference opened my eyes to the many passionate individuals who desire to impact the lives of people with disabilities! It is very exciting to see."
—Cari Brandt, University of St. Augustine, St. Augustine, FL

Please send me information on the World Congress & Exposition on Disabilities, September 18-20, 2003

I AM INTERESTED IN: ☐ Exhibiting at the Show ☐ Attending the Show

Name

Company

Address

City State Zip Code

Telephone Fax

Email

Send Me Information:
877-923-3976, x832
Fax this page to:
201-226-1236
Mail this page back to:
WCD
210 Route 4 East
Paramus, NJ 07652
Email your request from:
www.wcdexpo.com

For complete details, visit our website at www.wcdexpo.com, or call: (877) 923-3976 • (201) 226-1446

EP12/02

See You In September!

Returning to Orlando in 2003

September 18-20
Orlando, Florida

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD
4TH Annual
World Congress
& Exposition
on Disabilities
WCD or BUST!

SHOW PRODUCER: HAB H.A. BRUNO, LLC

IN ASSOCIATION WITH: EP Exceptional Parent

www.wcdexpo.com
(877) 923-3976
wcdinfo@wcdexpo.com

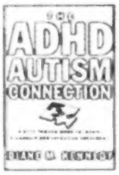
Circle #51 or visit www.eparent.com/adinfo

WWW.EPLIBRARY.COM
EP Exceptional Parent LIBRARY
THE SPECIAL NEEDS BOOKSTORE

AUTISM

LITTLE RAINMAN
Autism through the eyes of a child
KAREN L. SIMMONS
Written directly by Kren Simmons and indirectly by her autistic son, Jonathan, this was a script so that he could understand himself and his condition of autism. The story as written are the actual events in Jonathan's life. Includes many pictures to help those unable t read to also understand.
FN7295AT **$18.95**

TARGETING AUTISM
What We Know, Don't Know, and Can Do to Help Young Children with Autism and Related Disorders
SHIRLEY COHEN
This new updated edition is a road map of the world of autism for parents, educators, other clinical personnel, and students. Provides a broad framework and richer context of experiences along with conbeying the challenges and fascination of autism using the best current data available
UC4804AT **$14.95**



THE ADHD AUTISM CONNECTION
A Step Toward More Accurate Diagnosis and Effective Treatment
DIANE M. KENNEDY
At age two, Jessy Park was remote, withdrawn, unable to walk or talk, oddly content within the invisible walls that surrounded her. Doctors were baffled. The study of autism was still in its infancy. Jessy's family stepped in. This is one of the more interesting stories ever, a must read.
NEW
WP4980AD **$14.99**

A USER GUIDE TO THE GF/CF DIET FOR AUTISM, ASPERGER SYNDROME AND AD/HD
LUKE JACKSON; WITH APPENDICES BY JACQUI JACKSON; FOREWORD BY MARILYN LE BRETON
Luke Jackson, who is 12 years old and has Asperger Syndrome, tells you everything you need to know, both good and bad. He offers encouragement and practical advice on what to expect when beginning the gluten and casein free diet, how to alleviate any initial discomfort, and how to live with the diet.
NEW
TF0551AS **$17.95**

HEARING IMPAIRED

THE SILENT GARDEN
Raising Your Deaf Child Second Edition
PAUL W. OGDEN
An up to date reference comprising all the bits and pieces of advice, encouragement and hard data that parents might need in order to make decisions that will enable their children to grow into strong, healthy and productive members of society.
CU103DF **$29.95**

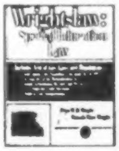
FOR YOUNG PEOPLE

IF THE WORLD WERE BLIND
A Book About Judgement And Prejudice
KAREN GEDIG BURNETT WITH ILLUSTRATIONS BY LAURIE BARROWS
This fascinatingly unique children's story is relevant to everyone, not just the children it is written for. You will find yourself asking how you view people, and what if, you couldn't view them at all?
GRP3040VI **$17.95**

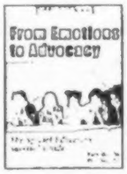
ALWAYS KISS ME GOODNIGHT
Instructions on raising the perfect parent
COMPILED BY J. S. SALT
Instructions on raising the perfect parent as seen in the eyes of 147 children. One of the most popular, entertaining, and insightful books a parent will ever find.
RM1090D **$7.00**

WHY AM I DIFFERENT?
NORMA SIMON WITH PICTURES BY DORA LEDER
This cute story tackles the idea of difference among children in every way except that of disability. That in itself makes the idea of difference easier to understand, accept, and overcome for any child, especially those that may feel more different that any other child.
AW0746YP **$13.95**

SPECIAL EDUCATION



WRIGHTSLAW: SPECIAL EDUCATION LAW
Includes Text of Key Laws and Regulations
PETER W.D. WRIGHT AND PAMELA DARR WRIGHT
This invaluable tool contains the full text of the Individual with Disabilities Education Act, FERPA, Section 504 of the Rehabilitation Act, implementing regulations, and decisions by the U.S. Supreme Court. Each of these statutes is explained and expounded upon by the authors in a way that enables all readers to understand the complex nature of special education law.
WP0037SE **$29.95**



WRIGHTSLAW: FROM EMOTIONS TO ADVOCACY
The Special Education Survival Guide
PAM WRIGHT AND PETE WRIGHT
Whether you are new to special education or an experienced advocate this book will provide you with a clear roadmap to effective advocacy for your child. A practical yet user-friendly text which includes hundreds of strategies, tips, references, warnings and resources. Designed to teach you how to plan, prepare and organize-and get quality special education services.
WP0088SE **$29.95**

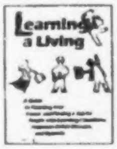
COPIOUS HOSTING
A Theology of Access for People with Disabilities
JENNIE WEISS BLOCK
This book smartly explores disability and theology in wonderfully contemporary terms. The author confesses not to speak for people with disabilities, yet masterfully examines the breadth and depth of the diverse disability community, and relates this body of knowledge to sometimes conservative theological tenets.
CI3496RE **$19.95**

EVERYBODY'S DIFFERENT
Understanding and Changing Our Reactions to Disabilities
NANCY B. MILLER & CATHERINE C. SAMMONS
This book is designed to provide the reader with a new awareness of disability differences in others, better understanding of their internal emotional reactions to disability differences and increased skills for interacting with people who have disability differences.
PR160GN **$21.95**

LEARNING DISABILITIES

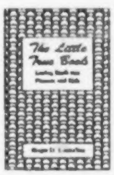
CHILDREN IN NEED OF SPECIAL CARE
THOMAS J. WEIHS, REVISED BY A.M. HAILEY, M.J. HAILEY, AND N.M. BLITZ
This book is a representation of the unique approach to learning disability that Dr. Thomas Weihs utilized. He saw it as not only a pathological condition which has to be remedied, but as a challenge to the self-knowledge and development of a parent or caregiver as well. This classic book explores the unique approach that values human beings as unique individuals.
IC5697GN **$16.95**

NO ONE TO PLAY WITH
Social Problems of LD and ADD Children
BETTY B. OSMAN
One of the first books that recognizes and provides advice on how to cope with the social difficulties encountered on an everyday basis by those with learning disabilities and attention deficit disorders.
AT100LD **$13.00**



LEARNING A LIVING
A Guide to Planning Your Career and Finding a Job for People With Learning Disabilities, ADD, and Dyslexia
DALE S. BROWN
A veritable cornucopia of information and tips about the impact of learning disabilities, feedback from others, useful mentor relationships, among other things. Whatever your career interests, this book will help you become successful in realizing your goals.
WB9675LD **$18.95**

RELIGION



THE LITTLE TRUTH BOOK
Loving Truth for Parents and Kids
ROGER D. CASTERLINE
Do you want a friend for keeps, a real friend? Well Roger D. Casterline will help you get acquainted with one, and his name is Jesus. This book is about relationships, not religion, and if you think you already know Jesus, you can still get to know him even better with the help of this book.
VA9031PA **$8.95**

BEHAVIOR

I Never Get Anything
How to Keep Your Kids from Running Your Life
Thomas W. Phelan, Ph.D.

From the time they are toddlers children try to "press their parents buttons" in order to get their way. In this balanced insightful book the author identifies the Six Kinds of Testing and Manipulation youngsters use to get their own way: Badgering, Temper, Threat, Martyrdom, Butter Up, and Physical Tactics. This practical and sometimes humorous guide explains to Moms and Dads exactly what to expect from frustrated kids and how to handle it — gently and firmly.

CMOL39BE **12.95**

Raising Children Who Refuse To Be Raised
Dave Ziegler, Ph.D.

This book is for both parents and professionals who are involved with the care of children who have severe emotional or behavioral disturbances as the result of abuse or neglect. The three major sections cover: Emotional disturbances, Where it all Begins; Behavioral Disturbances: There is More than Meets the Eye; and lastly Advanced parenting Skills and Challenges. The 12 chapters contain detailed discussions of emotional or behavioral disorders, their causes and possibilities for treatment.

AC87270N **$19.99**

GENERAL

Neuroimaging
A Window To The Neurological Foundations of Learning and Behavior in Children
G. Reid Lyon, Judith M. Rumsey

Explores the application of anatomical and functional neuroimaging techniques and procedures to the understanding of specific medical conditions and developmental disabilities in children. Includes two chapters covering the basic biological and methodological concepts needed to understand neuroimaging procedures.

PB2568NI **$49.95**

Putting Children First
Hanna McDonogh
and Christina Barthia

Besieged by multiple emotional, financial, legal, and practical stresses, divorcing parents are at heart often deeply worried and guilty about their children. This book provides ways for parents to develop the skills necessary to help their children in this period such as understanding grieving, relationships, mediation, court proceedings, and much more.

UT0642CN **$17.95**

The Shy Child
Helping Children Triumph Over Shyness
Ward K. Swallow

This authoritative interactive guide focuses on the problems of shyness and provides parents and children with pragmatic step-by-step solutions. It will help you achieve wonderful results such as stronger warmer relationships with family and friends, and a child who looks confidently to the future.

TW4990CN **$13.95**

Distant Drums, Different Drummers
A guide for young people with ADHD
Barbara D. Ingersoll, Ph. D.

A view that offers children and adolescents struggling with ADHD the opportunity to see them selves in a positive light due to their penchant for novelty and exploration and boundless energy.

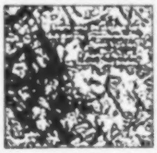
CP1000AD **$15.95**

BRAIN INJURY

The Experts Speak
Parenting the Child With Learning Disabilities
Teresa A. Citro

A clear, comprehensive, and direct collection of writings by professionals in the field of learning disabilities in their area of concentration. Whether it is teaching, parenting, or socialization there are stories on it here.

LD2001LD (English) **$18.99**
LD7129LD (Spanish) **$18.99**



Signs and Strategies for Educating Students with Brain Injuries
A Practical Guide for Teachers and Schools
G. Wolcott, M. Ed.,
M. Lash, M.S.W., &
S. Pearson, M.A.

Filled with useful guidelines, practical tips, and intervention strategies that enable parents and teachers to better understand the educational needs of children and adolescents with brain injuries.

HI1760D **$24.95**

Childhood Traumatic Brain Injury
diagnosis, Assessment and Intervention

A well balanced and comprehensive treatise on childhood traumatic brain injury. Covers a wide variety of issues surrounding brain injury in children from social expectations to assessment of skills.

PE1438I **$38.95**

VISUALLY IMPAIRED

Children with Visual Impairments
A Parents' Guide
Edited: M. Cay Holbrook, Ph.D.

Designed to help parents get a handle on common types of concerns. Written by a team of professionals and parents, each of whom is an expert on a different aspect of caring for children with visual impairments.

WB17900 **$16.95**

Transition Issues Related to Students with Visual Disabilities
Jane N. Erin and Karen E. Wolffe

An explanation and analysis of the critical areas in the lives of those with visual impairments, such as transportation, academics, employment and recreation.

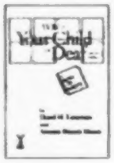
PE168VI **$12.95**

HEARING IMPAIRED

Kid-Friendly Parenting With Deaf and Hard Of Hearing Children
A Treasury of Fun Activities Toward Better Behavior
Daria Medwid and
Denise Chapman Weston

A step-by-step guide offering hundreds of ideas and methods designed to work with children ages 3 to 12 to enhance communication and strengthen relationships in skillful, fun ways.

CU1010F **$24.95**



When Your Child Is Deaf
A Guide for Parents
David M. Luterman with Antonia Brancia Maxon

This must read book provides information for parents about the emotional and educational processes of coming to grips with a hearing impairment in their child. Parents of newly diagnosed hearing impaired children as well as parents of a child with a hearing impairment at any age will find this book helpful.

YP22708I **$17.95**

Ask about our bulk order discounts for starting or refreshing your resource library

EXCEPTIONAL PARENT LIBRARY ORDER FORM

Mail to: **EP**, Dept. EP1202, P.O. Box 1807, Englewood Cliffs, NJ 07632-1207,
E-Mail: EPLIBRARY@AOL.COM, Fax (201) 947-9376, Or call **800•535•1910**

QTY.	ITEM#	UNIT PRICE	TOTAL
		Sub-Total	
		NJ Residents 6% Sales Tax	
		Shipping	
		TOTAL	

SHIPPING & HANDLING CHARGES:
U.S. – $4.00 for 1 item; 75¢ for each additional item.
Foreign – $7.00 for 1 item; 75¢ for each additional item.

U.S. funds only. Please allow 3-5 weeks for delivery. Returns must be made within 4 weeks of delivery. No overseas or video returns.

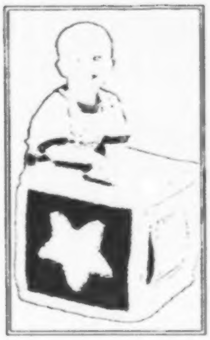
These prices are subject to change without notice.

Name ____________________
Address ____________________
City ____________________ State __________ Zip __________
Telephone ____________________ E-Mail ____________________
I have enclosed my check payable to Exceptional Parent or charge to my: ☐ Visa ☐ Mastercard ☐ AMEX ☐ Discover
Account Number: ____-____-____-____ Exp. Date ____/____

Signature ____________________

Circle #200

new products



JUMBO MUSIC BLOCK

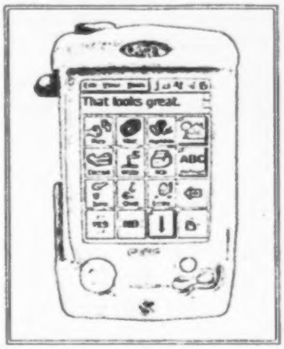
The Jumbo Music Block is an over sized plush toy with each side featuring a colorful geometric shape and two digitally recorded children's songs. These geometric shapes provide a secret pocket with a surprise activity inside. Manipulating the zipper, buttons, and Velcro closures reveal a surprise peek-a-boo mirror, ABC &123 book, and wiggly busy ball. The Jumbo Music Block is activated by an on and off switch and plays a song by simply turning the block over.

Neurosmith Customer Care, PO Box 14928, Long Beach, CA 90853; 800-220-3669
E-mail: customercare@neurosmith.com ; URL Web Site: http://www.neurosmith.com

CHAT PC

The Chat PC is a lightweight, portable augmentative communication aid with synthesized and digitized speech output. This pocketsize device has an on and off switch, volume control knob, amplified speaker and foam body armor for added protection. The Chat PC includes forty-five minutes to six hours of recording time, over three thousand picture symbols, two preprogrammed vocabulary sets and nine DECtalk voices for the synthesized speech output. This device also features a color touch screen with picture and text communication display pages and a rechargeable Lithium-Ion battery.

Mayer-Johnson, Inc., P O Box 1579, Solana Beach, CA 92075-7579; 800-588-4548, 858-550-0084,
858-550-0449 fax; E-mail: mayerj@mayer-johnson.com; URL Web Site: http://www.mayer-johnson.com



POLAR PET

The Polar Pet is a reusable cold pack intended to keep hands warm while acting as a cold compress. This plush toy is stored in the freezer until ready to be used. Simply apply the belly of the Polar Pet to the troubled area for cold therapy.

Masune First Aid & Safety, 500 Fillmore Avenue, Tonawanda, NY 14150 USA; 800-831-0894,
800-222-1934 fax; E-mail: info@masune.com; URL Web Site: http://www.masune.com

WHEELCHAIR ACCESSIBLE DESK WITH HEIGHT ADJUSTMENT & STORAGE

The Wheelchair Accessible Desk with Height Adjustment and Storage accommodates various age groups, wheelchair styles and wheelchair sizes. This desk features a wheelchair cutout, a book storage area on the side and height adjustment in one-inch increments. It also has a laminate top and a steel base with almond powder coated finish.

AS Furniture Solutions of Universal Design, 2728 South Cole Rd., Boise, ID 83709; 800-208-2020,
208-362-8009 fax; E-mail: customerservice@ad-as.com; URL Web Site: http://www.ad-as.com

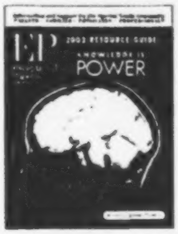
---

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

PRODUCT SHOWCASE

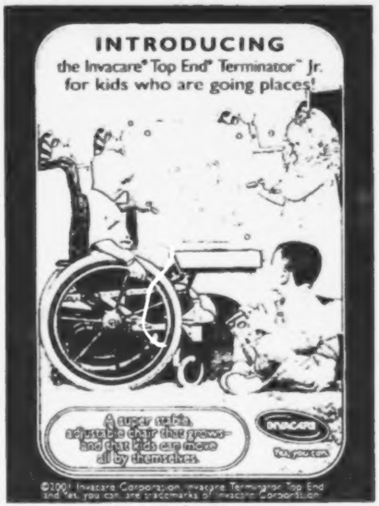
Product Showcase is a special service for EXCEPTIONAL PARENT readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.


EP
2002 RESOURCE GUIDE
KNOWLEDGE IS POWER

EXCEPTIONAL PARENT 2002 RESOURCE GUIDE

Directories of organizations, associations, products and services. The most complete guide to all the help you need: names, addresses, phones, and fax numbers of 1,500 resources. Just $19.95 (plus shipping/handling). To order, call 1-800-535-1910.

Circle #1


INTRODUCING
the Invacare® Top End® Terminator™ Jr.
for kids who are going places!
A super stable, adjustable chair that grows—and that kids can move all by themselves.
INVACARE
Yes, you can.
©2001 Invacare Corporation. Invacare, Terminator, Top End and Yes, you can. are trademarks of Invacare Corporation.

Circle #2

freedom
what is your definition?
call us today!
FREEDOM Concepts Inc.
1.800.661.9915
www.freedomconcepts.com

Circle #3

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16 or visit www.eparent.com/adinfo

EP neither endorses nor denies the effectiveness of this therapy.
For Editor-in-Chief statement see our Contents page.

Send us your child's photo!

EP is always looking for submissions for our monthly ***Familiar Faces*** column.

It may just end up on our cover!

Send to: EP, 65 East Route 4, River Edge, NJ 07661

Crystal Springs School

A PROGRAM OF THE
Institute for Developmental Diabilities, Inc.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeastern Massachusetts, close to Boston, Cape Cod, Providence and Newport, RI.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, Including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availablity.
- Licensed by the MA Office of Child Care Services.
- Approved by the MA Department of Education.
- Member of the MA Association of Approved Private Schools.

For information, Please Call Our Admissions Coordinator:
1-800-840-8087 (508) 644-3101 Ext: 375

Circle #24 or visit www.eparent.com/adinfo

MARKETPLACE

ACCESSIBLE TRAVEL

AFFORDABLE WHEELCHAIR VAN RENTALS

Orlando-Miami-Fort Lauderdale by Medical Travel Inc. Disney World Accessible Roll in Shower Villa's for RENT. Thinking of buying a Van—Price us Last. www.medicaltravel.org 1-800-778-7953

ATTORNEY/LEGAL

NATIONWIDE BIRTH INJURY ATTORNEYS

BURKE & EISNER, P.A.
1-800-566-3020
Cerebral Palsy, Brain Injury.
Ask for Jim, John or Dave.
Any one of us can help.
Online at www.cerebralpalsy.ws

BEACH WHEELCHAIR

Affordable Independence in the Great Outdoors!

The Features Make All the Difference!

Deming Designs Inc.
850-478-5765
850-476-3361 fax
www.beachwheelchair.com
call for free bochure

CHILDREN'S BOOKS

JASON & NORDIC
P.O. Box 441
Hollidaysburg, PA 16648
P: (814) 696-2920
F: (814) 696-4250

Free catalog upbeat stories, neat illustrations. For kids with disabilities and their friends.
Tackles real life issues.
www.jasonandnordic.com

EDUCATIONAL MATERIALS

DIFFERENT ROADS TO LEARNING
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057
A free catalog of learning materials and tools specializing in products used for Applied Behavioral Analysis; flash cards and manuals.
Website: http://www.difflearn.com

ATTAINMENT COMPANY
P.O. Box 930160
Verona, WI 53593-0160
800-327-4269
Special Products for Special Needs. Reinforce learning at home with the same materials that school districts use, at reduced prices! At AttainmentFamily.com we have a wide variety of products to help your child succeed at school, home and work. Visit us at www.attainmentfamily.com.

Special-Needs Collection

WOODBINE HOUSE
The Special-Needs Collection

60 books for kids, parents, & professionals on . . .

autism, AD/HD, celiac disease, cerebral palsy, deafness, Down syndrome, facial difference, fragile X syndrome, futures planning, inclusion, learning disabilities, special education, spina bifida, traumatic brain injury, and more.

Call for a FREE catalog (800-843-7323)
www.woodbinehouse.com

INCONTINENCE

ARC HOME HEALTH PRODUCTS
101 Browne St.
Oneonta, NY 13820
(800) 278-8595
Does ARC HHP have the lowest delivered price for ATTENDS & PREVAIL Youth Briefs? We think so. Contact us to find out. Many other brands, styles & sizes available. NY State Medicaid Provider.
Resource information:
www.medmarket.com
e-mail: info@archhp.com

Ask about our Youth/Small Brief sample pack.
Only $9.95

HDIS

FREE CATALOG

Call Today!
1-800-2MY-HOME®
(1-800-269-4663)

MONITORING SYSTEM

CARE ELECTRONICS INC.
4700 Sterling Drive, Suite D
Boulder, Colorado 80301
(303) 444-2273
www.careelectronics.com
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price.
Call for FREE CATALOG

SUPER DISCOUNTS

American Discount Medical

Super Discounts on all your Medical Equipment and Supplies plus FREE FREIGHT!

Don't Ever Pay Retail!

Save on Scooters Wheelchairs, Walkers and other Mobility equipment as well as Standers, Bath, Commode Chairs, Beds and all your Pediatric needs including Lifts, Strollers and respirtory items.

Discounts on all your favorite brands—Convaid, Pride, SnugSeat, Kaye, Otto Bock, Invacare, Columbia, Sammons-Preston, Porto-Lift, Wenzelite and many, many more.

For more information and our FREE Brochure call:
(800) 877-9100
Or Visit us on the Web @ www.AmericanDiscountMed.com
Our E-Mail address is:
adm@information4u.com

SWINGS

Portable Swing Stand

Therapy Swings

Safe, strong comforting & affordable for all your swinging and spinning needs

For more information contact
Take-A-Swing LLC
602-451-5544 • www.takeaswing.com

VAN CONVERSION DEALERS

MASSACHUSETTS

MOTION AUTOMOTIVE SPECIALTY
Rt. 20 Forest Business Park
Brimfield, MA 01010
(413) 245-9949 or (800) 955-9949
www.motionautomotive.com
Mobility at it's best. Complete van & adaptive conversions.
Authorized Dealer.
Accessible Van Rentals—Day, Week or Month.

TO ADVERTISE IN MARKETPLACE CONTACT:

Barbara Nastro
TEL: (908) 534-6366
FAX: (908) 534-6941

familiar faces

SOPHIE

Sophie Pettman, 2, loves Christmas. She has chromosome 9qt. She loves music, dancing and is happy to cuddle-up and read books with anyone willing. Her parents refer to her as their "little angel."

JAVONTE

Javonte Forbes, 3, gets a lot of love from his cousin Ernestine (hugging him), who adores him very much. JJ has cerebral palsy, but that doesn't stop him from smiling, laughing and walking around in his walker. He is an only child but loves his therapy sessions because he gets to play with other kids his age. He also enjoys watching television while rocking in his chair. A few of his favorite shows include "Sponge Bob Square Pants," "Dora," "Blues Clues" and "Sesame Street."

ALEX

Alexander Franklin Sing was born with Mohr-Majewski Syndrome and Oral-Facial-Digital Syndrome II. Assistance comes from a trach, oxygen tank and a ventilator. Alex is always thinking about his future. Some dreams are to become a teacher, writer, or an actor. He loves his family and friends. His favorite leisure activities include reading a good fantasy book and watching wrestling.

KIMBERLY

Kimberly Yuknig, 2, lives at home with her mom, dad and two German Shepard dogs, Cleo (left) and Thunder (right). She has periventricular leukomalacia and CP. She loves singing, swimming, yoga, Pooh Bear and "Blue's Clues."

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EP? Send it to: Readers' Photos, EP (Exceptional Parent), 65 E. Route 4, River Edge, NJ 07661. (Please do not send "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

My Favorite Cousin

By: Andrea Tocci

Gabi and Andrea

Gabrielle Nicole Statltare is my cousin, my favorite cousin. She has brown curly hair, beautiful brown eyes and a smile that makes me happy. She laughs at silly things and cries when she is sad. She has a little sister named Victoria. Gabi is her nickname and the moment people meet her they love her.

Gabi was born on May 10, 1994. Everyone was so excited. Unfortunately, due to a doctor's error, Gabi lost oxygen to her brain, which resulted in many disabilities, including low vision and mainly cerebral palsy. This means that Gabi can't walk unaided; at least, not yet! Gabi also cannot speak too well but she will let you know when she wants something! I am proud because my name is one of the names she can say.

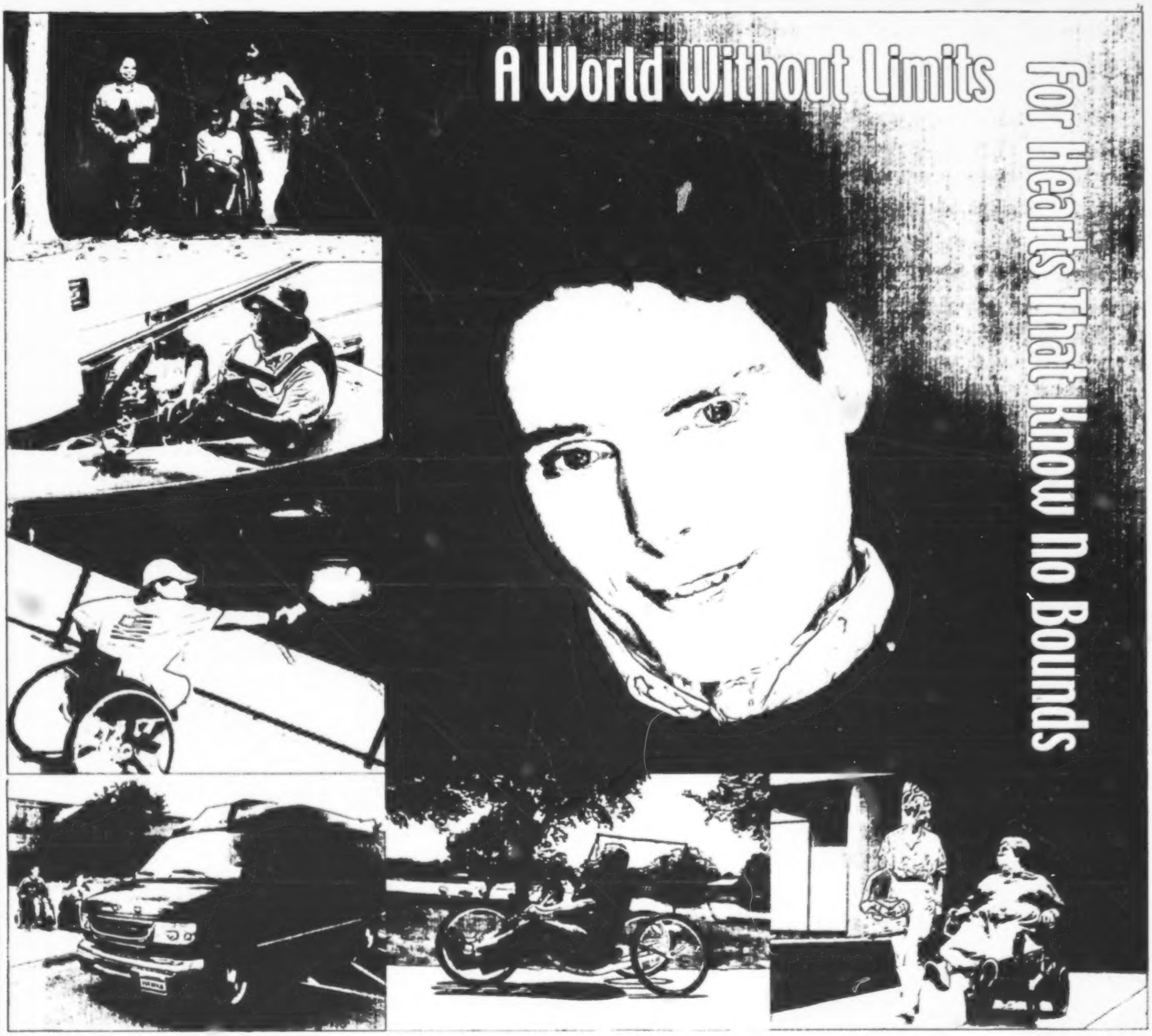
At first, I was nervous around Gabi because I thought I would hurt her. After I got to know her special needs I wasn't nervous anymore. Gabi has always been treated like any other kid. Even though she has many people to care for her we still have fun together. Gabi squeals in delight when she pulls my hair and I act like she is hurting me. Some of the first amusement park rides Gabi went on, I was right behind her, holding her and laughing along with her. Gabi and I have a special bond that only we share.

In October of 1995 Gabi and her mom, my Aunt Garbara, were invited to St. Patrick's Cathedral in New York City for a special mass. It was the year that Pope John Paul II was in the United States. My Aunt Barbara made her way to the front row where Mayor Giuliani was sitting. When the Pope came down the aisle he stopped at Gabi and took her from my Aunt's arms. He held her and asked my Aunt what her illness was and my Aunt told him. Pope John Paul II kissed Gabi's left eye and told my Aunt that he would pray for her. When we found out that Gabi's vision had improved in her left eye we knew it was a miracle.

Gabi goes to a great school in Long Island, NY called the Carmen Road School for Physically Handicapped Children. They do so many things to encourage growth in body, mind and spirit. Gabi makes some awesome things at her school. During the school year Gabi's teachers send me cards from her. The cards are so special to me. In the summer Gabi goes to Camp Anchor. It is a special summer camp for children with special needs. They go in the pool, play games, make crafts and go on field trips. At the end of the summer they have a carnival and I get to go and see Gabi's friends and teachers. Because of how happy Camp Anchor makes Gabi and other children I am hoping to one day work there.

I think Gabi's life is an inspiration to me because she is very brave and courageous. She works so hard to do things that we take for granted. When I think about how hard it is to do something, I think about Gabi and it gives me courage to do it. I know Gabi will live a happy and fulfilling life because she has so many people that love and encourage her. I have found through Gabi that love comes from within your heart. EP

Submit your Children's Page to: EP, ATTN: CHILDREN'S PAGE, 65 East Route 4, River Edge, NJ 07661. Be sure to include your name, address, daytime telephone number and e-mail address! ***Now on the Web!*** We now include **Familiar Faces** and **Children's Page** on our Web site, http://www.eparent.com. Please send us your photographs with the understanding that doing so gives EP permission to put the photos on the EP Web site, exactly as they appear in the magazine and with the same text.


A World Without Limits
For Hearts That Know No Bounds

For more than ten years Ford Mobility Motoring has been Ford Motor Company's better idea of a comprehensive process of financial assistance, adaptive equipment information and credit assistance for Ford customers with disabilities and their families.

- Ford, Mercury and Lincoln cars, vans and light trucks. **Vehicle solutions** for every adaptive equipment need!
- Ford Credit Financing provides **purchase and lease solutions** accommodating the special vehicle needs of persons with disabilities and their families.
- Up to **$1,000 in financial assistance** for adding adaptive equipment to eligible Ford, Mercury and Lincoln vehicles.[1]
- Adaptive equipment assessment centers and installer **resource listings** tailored to every state.

Begin your Ford Mobility Motoring experience by calling Program Headquarters.

1-800-952-2248 or
TTY 1-800-833-0312

Visit us on the World Wide Web
www.mobilitymotoringprogram.com

Ford Motor Company
MOBILITY MOTORING

Ford Credit

MOBILITY FINANCING

CHRISTOPHER REEVE
PARALYSIS FOUNDATION

The Christopher Reeve Paralysis Foundation (CRPF) encourages and supports research to develop effective treatments and a cure for paralysis caused by spinal cord injury and other central nervous system disorders. The foundation evaluates and selects these research programs using councils of internationally renowned neuroscientists and clinicians. The Foundation also allocates a portion of its resources to grants that improve the quality of life for people with disabilities.

---

[1] The 2003 Ford Mobility Motoring Program is in effect from September 1, 2002 through August 31, 2003. The Ford Mobility Motoring Program will reimburse for the exact amount of the adaptation, up to $1,000 on adaptive equipment and up to a maximum amount of $200 for alert hearing devices, lumbar support and running boards, when you take retail delivery of a new 2002, 2003 or 2004 Ford, Mercury or Lincoln vehicle by August 31, 2003. Total reimbursement is not to exceed $1,000.

Circle #29 or visit www.eparent.com/adinfo

MA7503/08-02

A Better Bedtime Story

The Vail Enclosed Bed

Once upon a time, parents of special-needs children dreamed of a way to make bedtime easier and safer. With Vail Beds, everyone sleeps happily ever after. Your child enjoys the soft, non-threatening security of an enclosed hospital bed—while you enjoy peace of mind knowing they are protected during the night. Vail Enclosed Beds:

- Protect against falls and injuries.
- Reduce wandering.
- Encourage more relaxed sleep—for you child and you.

Vail Beds also accommodate medical equipment; fit all ages from child to adult; feature lifetime service; and come complete with mattress, manually adjustable hospital bed and vinyl border and bedskirt.

Plus, we provide assistance in obtaining insurance approval.

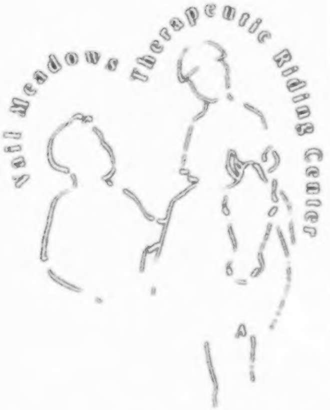
Available from home health-care products dealers, or direct from th manufacturer.

For a FREE catalog, call:
1-800-235-VAIL

Vail
Enclosed
Bed
Systems

Toledo, Ohio
www.vailbed.com

VISA MasterCard


Vail Meadows Therapeutic Riding Center

Corporate Sponsor of
Vail Meadows
Therapeutic Riding
Center

Happy challenges for challenged riders.

Ask about Our Decorator Accessories.

“Allison had trouble falling asleep due to neurological damage. But the Vail bed has changed our lives. She loves it! And it's like her neurologist told us: the bed has conditioned her to fall asleep.”

Sheri Wittmer
Sandusky, Ohio

1422

Circle #48 or visit www.eparent.com/adinfo

U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)

ERIC
Educational Resources Information Center

NOTICE

Reproduction Basis

☒ This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.

☐ This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").

EFF-089 (1/2003)